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THE HOSPICE ALTERNATIVE

ORIGINAL

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

NINETY-SEVENTH CONGRESS

SECOND SESSION

PITTSBURGH, PA.

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CONTENTS

Page

Opening statement by Senator John Heinz, chairman 1

CHRONOLOGICAL LIST OF WITNESSES

Decker, Philip G., director, Hospice St. John, Kingston, Pa., and Mid-Atlantic coordinator, National Hospice Education Project 2
Shope, Earl S., M.D., medical director, Windber Palliative Care Unit, Windber Hospital, Windber, Pa 8
Luckock, Bill, Pittsburgh, Pa 20
Siciliano, Virginia, Oakmont, Pa 22
Walton, Ellen, volunteer, Forbes Hospice, Pittsburgh, Pa 26
Fello, Maryanne, assistant executive director, Forbes Hospice, Pittsburgh, Pa .. 31
Cohen, Frances W., executive director, South Hills Family Hospice program, Pittsburgh, Pa 35
Bohnet, Nancy L., R.N., coordinator, Allegheny Home Care Hospice, Northeast Allegheny Home Health Agency, Pittsburgh, Pa 39
De Moss, Carol J., R.N., M.N., C.S., nurse clinician, in-home hospice service, Visiting Nurse Association of Allegheny County, Pittsburgh, Pa 42

APPENDIX

Statements submitted for the record:
Item 1. Statement of Denise Koppelman Harris, executive director, Hospice of Greene County, Inc., Waynesburg, Pa 55
Item 2. Statement of Hospice of York, Pa 56
Item 3. Statement of Madalon O'Rawe Amenta, R.N., Ph. D., president, Pennsylvania Hospice Network, Pittsburgh, Pa 62
Item 4. Statement of Barrie R. Cassileth, Ph. D., director, palliative care program, University of Pennsylvania Cancer Center, Philadelphia, Pa ... 62

THE HOSPICE ALTERNATIVE

MONDAY, MAY 24, 1982

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Pittsburgh, Pa.

The committee met, pursuant to notice, at 9:20 a.m., in the School of Public Health Auditorium, University of Pittsburgh, Pittsburgh, Pa., Hon. John Heinz, chairman, presiding.

Present: Senator Heinz.

Also present: Ann Langley and Michael Rodgers, professional staff members; and Kathleen M. Deignan, minority professional staff member.

OPENING STATEMENT BY SENATOR JOHN HEINZ, CHAIRMAN

Senator HEINZ. Ladies and gentlemen, I am pleased to welcome you here today for this Senate Special Committee on Aging hearing on the hospice alternative.

As most of you know, hospice is a method of caring for the terminally ill. As chairman of the Special Committee on Aging, I have a particular interest in hospice because of its special relevance to the elderly. Older persons account for over half of those suffering from a prolonged terminal illness in this country, and 50 to 70 percent of hospice patients nationwide are over the age of 65.

But the concept of hospice is important to all age groups. Most of us have experienced a significant loss at some time in our lives. We have a common bond that motivates us to help others cope with such experiences. The growth of what is referred to as the "hospice movement" has brought long overdue attention to how we as individuals and as a society deal with the last days of life.

Through modern medicine, we have achieved technological advances in cardiology and other aspects of health care which have helped to prolong life. But this has led to a system of care which focuses almost exclusively on curing illness and high-technology/hospital-based medicine. The special needs of those for whom there is no cure are often neglected. Hospice is an alternative method of caring developed to meet those needs.

Hospice care emphasizes the quality of the last days of life, and helps the terminally ill continue their lives with as little disruption as possible. It differs from traditional medical care in four major respects:

First, care is directed toward maintaining the functional abilities of the patient and controlling pain, rather than technical, cure-oriented treatment.

Second, the family is involved and supported in caring for the dying person.

Third, hospice programs provide the choice of home care, instead of relying on institutional care. Inpatient facilities, hospitals or nursing homes, are provided whenever needed.

Fourth, the emotional needs of the terminally ill and their families are given as much attention as their medical needs.

For many people, the hospice alternative may offer a more humane way of coping with their illness. It promises to be an effective substitute for traditional institutional care—both medically and emotionally—and probably costs no more than the institutional services currently provided to the terminally ill. Yet, despite this promise, the Government's largest health care reimbursement system—medicare—and most private insurers do not recognize these important services. This lack of recognition is mainly due to the fact that the major growth in the hospice movement has occurred in only the last few years. The first U.S. hospice program was established in 1971, 6 years after the medicare program began. Hospice care was not available in Pennsylvania until 1978, and over 50 percent of the hospices in this country are no more than 1 year old.

But the demand for hospice care as it becomes more widely known has been phenomenal. The number of hospices has increased eightfold in the last 3 years. As of July 1981, there were 400 operational and over 400 planned hospices nationwide, and hospice care is now available in every State. Pennsylvania now has 51 to 60 known hospices in various stages of development.

I believe that it is time that we in Congress recognize this important form of care. Over 300,000 older Americans will be denied access to hospice care unless archaic medicare laws are changed. More than $4 billion in medicare are spent annually for the last 40 days of life—but that coverage is not available to those who chose to ease the pain of a terminal illness in a comfortable, family setting. The medicare program needs to be brought up to date with the growing utilization of hospice care across the country. That is why, in December of last year, I cosponsored legislation, S. 1958, which would allow medicare reimbursement for hospice.

This hearing we are holding today is the first hearing to be held in the Senate on hospice. I am pleased that we have so many excellent providers of hospice services, and families and volunteers, in western Pennsylvania to help us increase public and congressional awareness about this important alternative for the terminally ill.

Our first witnesses today will be Phil Decker and Dr. Earl S. Shope. Phil Decker is director of the Hospice St. John, and I would like to ask Phil to be our first witness.

STATEMENT OF PHILIP G. DECKER, DIRECTOR, HOSPICE ST. JOHN, KINGSTON, PA., AND MID-ATLANTIC COORDINATOR, NATIONAL HOSPICE EDUCATION PROJECT

Mr. DECKER. Thank you, Senator Heinz. Before I begin my statement regarding hospice care and hospice reimbursement, I along with thousands of hospice recipients and providers would like to publicly applaud Senator John Heinz for all of his efforts and his

support in sponsoring S. 1958, the hospice reimbursement bill. This bill, when enacted, will allow terminally ill medicare patients to choose the right to a hospice benefit. This benefit, as explained in the testimony you are about to hear, is much more appropriate, compassionate and often less expensive.

Today in the United States, as in Europe, hospice has been designated as the program of care providing for the special needs of the dying patient and their family members. The hospice philosophy affirms life, not death. Hospice exists to provide support and care for patients in the last phases of incurable disease so that they might live as fully and as comfortably as possible.

Unique characteristics of hospice, as you have mentioned, embrace the family as the unit of care, the care is provided by a multidisciplinary team, the care is available on a 24-hour day, 7-days-a-week basis and is under the direction of a physician. This care continues into the bereavement period. I think an important component of the hospice philosophy is that hospice recognizes dying as a normal process. Acceptance of a patient and family in the hospice program is not based on the ability to pay but upon need—medical need.

Although fewer than 8 years have passed since the opening of the first hospice in the United States, today there are hospice programs, as you have mentioned, Senator, in every State. In fact, it is estimated that there are more than 400 programs in the country today delivering service and another 400 being developed. Apparently hospice services are in more demand with increased numbers looking for hospice care, and if hospice care is more appropriate and certainly no more expensive and ultimately more humane for the treatment of our Nation's terminally ill, what obstacles block the further development of hospices in America?

Dennis Rezendes, founder of the National Hospice Organization and past director of the Nation's first hospice in New Haven, Conn., stated, "The single greatest obstacle to the progress and even the survival of the hospice movement in America is the current health insurance and reimbursement system."

Despite the apparent cost savings to a health insurer when a patient chooses hospice care, a dying person may be financially penalized for that choice.

A provider of health care services penalizes itself financially when making hospice services available instead of keeping all terminally ill persons in the more costly, traditional acute care setting. And this does not consider the quality of life nor the appropriateness of care for that terminally ill individual.

Though the first hospice patient was cared for in America more than 7 years ago, hospice per se is still not mentioned as a covered service in the present medicare system. As a result, Government policy is in effect saying to this terminally ill patient:

If you will choose acute care hospitalization at a cost of $300 or more per day, we will be delighted to be responsible on your behalf so that providers will accept what we pay as full payment for health services. If you choose hospice care, at certainly no more and probably less we may or may not pay a portion of the bill, depending upon a number of variables, and you can never expect us to arrange for full payment.

The same reimbursement policy, again unconsciously, says to the provider of health care services:

> If you will admit the terminally ill person into the hospital, perform the usual routine admission tests, place the patient in an acute care bed or an intensive care unit, accomplish enough repetitive diagnostic work, we would be delighted to reimburse you. However, should you be devoted to palliating the patient's symptoms, developing and sustaining a support system at home, and then getting the person home and keeping him there as long as possible, all under the auspices of hospice, then we will reward you with substantially less reimbursement or, more likely, no reimbursement at all.

It can be said that the current governmental policy is to reward and encourage high health care costs for the terminally ill, while discouraging and not recognizing more appropriate, lower cost hospice alternatives in those cases where hospice care is both desired and appropriate for the patient involved.

There have been many studies done to support the hospice philosophy and benefit, especially related to costs. One of the studies I am referring to was done at Methodist Hospital in Jacksonville, Fla., where cost comparisons have been done. It has been shown that, on an average, comparing similar patients in the medicare system and in hospice care, the average cost per day of patients who would be eligible for hospice care if it were available was $309 a day.

In June 1980, when Methodist Hospital opened a hospice program, similar studies were done on patients who were admitted to the hospice program with similar diagnoses and prognoses. The average cost for those individuals was $162 per day, with an average length of stay at home and in the facility, more appropriate to terminal care.

Dr. Marcus E. Drewa, president of the American Protestant Hospital Association and president of Methodist Hospital, says:

> Though we are proud of our hospice program and pleased with the cost comparisons, we are concerned about the cost reporting implications of our hospice. If we identified hospice patients as hospice patients and hospice services as hospice services, instead of burying it in the acute care language, we would probably be rewarded for our efforts with drastic massive disallowances.

Attorney David H. Eisenstat, who is a leading authority on how hospice relates to the present medicare system, says:

> One need look no further than the list of waivers under the HCFA demonstration program for examples of potential fraud and abuse. If I were a prosecutor, I could not help but ask, "How has reimbursement been obtained in the past without the waivers?" Additionally, a recent survey of Blue Cross plans turned up evidence that a substantial number of hospice-type services have been traditionally reimbursed as a part of general administrative and overhead costs rather than through specific line items.

There are many hospice programs in the United States that are unaffiliated with any current medicare provider. These free-standing hospice programs of care, and their patients, are most exposed and most vulnerable to a system which discriminates against hospice. They have no reimbursement umbrella to sustain them and insure their financial viability.

Their plight is best illustrated by the fate of two pioneer hospices in this country, Riverside Hospice in Boonton, N.J., and Hillhaven Hospice, in Tucson, Ariz. Both have been forced to either close or fold back their services into acute care facilities because of the loss

of adequate reimbursement. The patients who would have utilized their fine services have rejoined the acute care system, at acute care costs.

Dr. Daniel C. Hadlock, immediate past president of the National Hospice Organization, says:

> Unless the inequities in the reimbursement system are resolved, I expect 50 to 100 more hospice programs of care currently operating in America to fold within the next 2 to 3 years. Thousands of dying persons and their families will be denied the hospice option and will place an unnecessary financial burden on medicare primarily, and on the private insurance carriers as well.

There is a solution to the hospice reimbursement dilemma. That solution is the passage of S. 1958, the hospice reimbursement bill. Numerous studies, demonstrations, and cost analyses have already been completed and there is ample evidence that the inclusion of a comprehensive hospice benefit in the medicare system would result in comparative cost savings.

In closing, if hospice care is to become a viable integrated part of the American health care system, then passage of S. 1958 is timely and urgent.

Thank you, Senator Heinz.

Senator HEINZ. Thank you, Phil. You did omit parts of your statement from your written statement and your oral presentation. Without objection, we will make sure that your entire statement is made a part of the record. In particular, Mr. Eisenstat had a good deal more to say than you quoted him on, which I think is very valuable and we want to be sure that gets in the record.

[The prepared statement of Mr. Decker follows:]

PREPARED STATEMENT OF PHILIP G. DECKER

My name is Philip Decker, and before I begin my statement regarding hospice care/hospice reimbursement, I, along with thousands of hospice recipients and providers, would like to publicly applaud Senator John Heinz for his efforts and support in sponsoring S. 1958 (the hospice reimbursement bill). This bill, when enacted, will allow terminally ill medicare patients the right to choose the often more appropriate, compassionate and less expensive hospice benefit.

I appear before you today as the director of Hospice Saint John, a division of Lutheran Welfare Service of northeastern Pennsylvania, board member of the Pennsylvania Hospice Network, chairman of the legislative committee of the board, member of the steering committee of the National Hospice Education Project and regional coordinator for the Middle Atlantic States of that project.

Today in the United States, as in Europe, hospice has been designated as a program of care providing for the special needs of the dying person and their family members.

The hospice philosophy affirms life.—Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortable as possible.

Unique characteristics of hospice care include:

(1) Embracing the family as the unit of care.

(2) The care is provided by a multidisciplinary team.

(3) The care is available on a 24-hour, 7-day-a-week basis either in the family's home or in a hospice inpatient unit.

(4) The care is under direction of a physician.

(5) Care continues during the period of grief and bereavement.

(6) Hospice recognizes dying as a normal process. Hospice neither hastens nor postpones death.

(7) Acceptance of a patient/family to a hospice program of care is not determined by the ability to pay but rather upon the appropriateness of the referral-medical need.

In Pennsylvania, the hospice movement first surfaced to the attention of the Pennsylvania Department of Health in 1978. Upon investigation by the department,

it was learned that approximately 11 agencies were interested in providing hospice care—Hospice Saint John being one of the 11. In January 1979, this number grew to 20 organizations across the Commonwealth either interested in or already providing hospice care in Pennsylvania.

In February 1980, the "Task Force on Hospice" was established by the Governor's office to explore issues surrounding the interest and provision of hospice care in Pennsylvania. A four-phase, data gathering process was developed by the "task force" and a report containing recommendations to the Governor's office will be available in several months.

Simultaneously, the Pennsylvania Hospice Network had its initial organizational meeting at the National Hospice Organization annual meeting in November of 1980 in Cincinnati. Since that time, the Pennsylvania Hospice Network has grown into a network of health care agencies and individuals committed to the furtherance of the principles of hospice care in Pennsylvania. Today, there are 54 organizational and 80 individual members of the Pennsylvania Hospice Network.

Although fewer than 8 years have passed since the opening of the first hospice in the United States, today there are hospice programs in every State. In fact, it is estimated that there are more than 400 hospice programs delivering or planning to deliver hospice services across the country.

With hospice services in more demand and if hospice care is often more appropriate, certainly no more expensive, and ultimately more humane for our Nation's terminally ill, what obstacles block the further development of hospice in America?

Dennis Rezendes, founder of the National Hospice Organization and past director of the Nation's first hospice in New Haven, Conn., said:

"The single greatest obstacle to the progress and even the survival of the hospice movement in America is the current health insurance and reimbursement system."

Despite the apparent cost savings by a health insuror when a patient chooses hospice care, a dying person may be financially penalized for that choice.

A provider of health care services penalizes itself financially when making hospice services available instead of keeping all terminally ill persons in the more costly, traditional acute care setting. And this does not consider the quality of life or appropriateness of care for the terminally ill individual.

Though the first hospice patient was cared for in America 7 years ago, hospice, per se, is not yet mentioned as a covered service for medicare purposes in the Social Security Act.

As a result, governmental policy is, in effect, saying to the terminally ill patient: "If you will choose acute care hospitalization at a cost of $300 or more per day, we will be delighted to be responsible on your behalf so that providers will accept what we pay as full payment for health services. If you choose hospice care, at certainly no more and probably less cost per day, we may or may not pay a portion of the bill, depending upon a number of variables, and you can never expect us to arrange for full payment."

The same reimbursement policy, again unconsciously, says to the provider of health care services: "If you will admit the terminally ill person into the hospital, perform the usual routine admission tests, place the patient in an acute care bed or an intensive care unit, accomplish enough repetitive diagnostic work, and perhaps use some surgery to help justify the stay, we will be delighted to reimburse you. However, should you be devoted to palliating the patient's symptoms, developing and sustaining a support system at home, and then getting the person home and keeping him at home where he wants to be, all under the auspices of hospice, then we will reward you with substantially less reimbursement or, more likely, no reimbursement at all."

In any case, the provider may be committing medicare fraud by even billing for and accepting what little reimbursement he can get because the word "Hospice" is not in our regulations book yet.

It can be said that current governmental policy is to reward and encourage high health care costs for the terminally ill while discouraging and not recognizing more appropriate, lower cost hospice alternatives in those cases where hospice care is both desired and appropriate for the patient involved.

A study of terminally ill cancer patients cared for at Methodist Hospital, Jacksonville, Fla., over a 6-month period indicated that 42 medicare patients who would have met hospice admission criteria but who, for lack of access to hospice, had episodes of acute care accounting for an average of 26 days per patient in the hospital at an average per day cost to the medicare system of $309.

In June of 1980, Methodist opened a comprehensive hospice program of inpatient and home care.

During the first 6 months of hospice care, 111 patients were admitted into the program. Sixty-two of these required inpatient hospice care at an average per diem cost (total all inclusive cost) of $162 with an average inpatient length of stay of 11 days. Aside from hospice inpatient stays, this group of patients accounted, totally, for an additional 9 days of acute care hospitalization at approximately $325 per day.

The other days of care during the final 6 months of these patients' lives were spent in their own homes. The average cost per day for the hospice team to provide 24-hour, 7-day-a-week access to hospice services was $16.40 per day with an average per visit of $35. This compares to the lower quadrant of what licensed home health agencies in Florida charge medicare for merely a skilled nursing visit.

Methodist Hospice is an example of those institutionally based hospice programs in the Nation who are trying to make the octagon-shaped hospice peg fit into the round reimbursement hole.

Dr. Marcus E. Drewa, president of the American Protestant Hospital Association and president of Methodist Hospital, says:

"Though we are proud of our hospice program and pleased with the cost comparisons, we are concerned about the cost reporting implications of our hospice. If we identified hospice patients as hospice patients and hospice services as hospice services instead of burying it all in acute care cost reporting language, we would probably be rewarded for our hospice efforts with massive disallowances."

Attorney David H. Eisenstat, one of the most knowledgeable legal authorities in how hospice relates to the existing reimbursement system, pointed to a significant legal dilemma for hospices and for the government if the current reimbursement statutes are not changed:

"How does fraud and abuse affect hospices specifically? In one sense, hospices are impacted in much the same way as any other provider, and in this respect, potential problems may arise in any number of ways. For example, each time a medicare or medicaid patient complains that he or she did not receive a particular injection or see a physician as indicated on the patient's bill, there is a problem inviting investigation. When allegations of this sort are proven and the billing entries were made knowingly, there may be violation of the statute's fraud provisions. Even when inadvertent, such entries may result in allegations of program abuse. As an aside, the line between fraud as opposed to abuse is, to say the least, a narrow one—one government official defined the term 'abuse' as any practice he didn't like but doubted he could obtain a 'fraud' conviction for. I've even heard 'abuse' defined for purposes of the statute as reimbursement maximization. The point is that these statutes provide a great deal of prosecutorial discretion, and as a hospice provider—running a novel program with a high degree of public visibility—I would be extremely wary of exposing myself to the whims of zealous government prosecutors (of which there are many).

"Hospice programs may be uniquely vulnerable to investigation and prosecution. To the extent that hospices have successfully garnered reimbursement in the past, they have done so largely by defining components of hospice care along the dimensions of existing covered services. This 'round-peg-in-a-square-hole' approach to reimbursement, which I described earlier, may arguably give rise to a prosecutorial theory of fraud or abuse. My concern is that an aggressive and innovative prosecutor could turn a critical eye upon program payments received in the past by hospice programs and make out a convincing case that the narrow line between covered service and nonallowable cost has been unlawfully breached.

"One need look no further than the list of waivers under the HCFA demonstration program for examples of potential fraud and abuse vulnerability. If I were prosecutor, I could not help but ask: 'How has reimbursement been obtained in the past without the waivers? Additionally, a recent survey of Blue Cross plans turned up evidence that a substantial number of hospice-type services have been traditionally reimbursed as a part of general administrative and overhead costs, rather than as specific line items. This effective 'burying' of hospice-type costs, albeit perhaps with the tacit endorsement of third-party payors, has a significant potential for fraud and abuse prosection."

There are many hospice programs of care unaffiliated with any current medicare provider. These free-standing hospice programs of care and their patients are the most exposed and most vulnerable to a system which discriminates against hospice. They have no reimbursement umbrella to sustain them and insure their financial viability.

Their plight is best illustrated by the fate of two pioneer hospices in this country, Riverside Hospice, Boonton, N.J., and Hillhaven Hospice, Tucson, Ariz. Both have been forced to either close or fold their services back into acute care models because

of the absence of adequate reimbursement. The patients who would have utilized their fine services have rejoined the acute care system, at acute care costs.

Dr. Daniel C. Hadlock, immediate past president of the National Hospice organization, says:

"Unless the inequities in the reimbursement system are resolved, I expect 50 to 100 more hospice programs of care currently operating in America to fold within the next 2 to 3 years. Thousands of dying persons and their families will be denied the hospice option and will place an unnecessary financial burden on medicare, primarily, and on the private insurance carriers, as well."

There is a solution to the hospice reimbursement dilemma. That solution is the passage of S. 1958, the hospice reimbursement bill.

This bill will amend part A of title XVIII of the Social Security Act to provide that all Americans now eligible for medicare would have a hospice benefit added to their hospital insurance coverage. It seems apparent that this action would benefit not only the terminally ill who need hospice care, but also the medicare system as well.

Numerous studies, demonstrations, and cost analyses have already been completed and there is ample evidence that inclusion of a comprehensive hospice benefit in the medicare system will result in comparative cost savings.

In closing, if hospice care is to become a viable integrated part of the American health care system, then passage of S. 1958 is timely and urgent.

Senator HEINZ. Our next witness is Dr. Earl S. Shope, medical director at the Windber Palliative Care Unit, Windber, Pa.

STATEMENT OF EARL S. SHOPE, M.D., MEDICAL DIRECTOR, WINDBER PALLIATIVE CARE UNIT, WINDBER HOSPITAL, WINDBER, PA.

Dr. SHOPE. Senator Heinz and ladies and gentlemen, you will have to bear with me if I seem a little nervous. I am more at home taking cases than I am here testifying before a Senate committee.

In 1981, these figures were available: Roughly 805,000 people in this country developed cancer, and roughly 430,000 of these people died of the disease. We are talking about one person every 75 seconds or roughly 1,150 people every 24 hours. Sixty percent of all cancer patients eventually die of their disease. This is the major pool of terminally ill patients in this country, although cardiovascular disease and certain degenerative diseases add a small amount.

I remember beginning practice roughly 10 or 12 years ago and walking down a hospital corridor, I would hear cancer patients writhing in pain and dying a very horrible and very horrendous death. It became pretty obvious to me at that time, even though I was not practicing cancer therapeutics, that this was a generation that was vastly affected by society and by medicine in general.

In 1977, 4½ years ago, we decided to institute a palliative program, a hospice program in the Windber area to take care of these patients. At that time, we elected to involve the family physicians, nurses, social workers, lawyers, housewives, any volunteers who wished to be involved with patient care. We also agreed to involve any social services in the community so we would not overlap services, and so there would be a comprehensive outpatient process for these individuals. The team at that time was charged with the idea of identifying any of the problems facing a patient family unit, and through the years we have identified the focus of care, which is directed to provide successful management of pain and suffering associated with terminal illness. We also provide a cheerful environment that will assist a person to die with dignity. We also were

charged to permit persons in the family the right to become involved in the plan of care, also to blend the skills of nurses, doctors, social workers, clergy, volunteers and others who wished to be involved with the dying person; also to help the survivors in the grieving process and to demonstrate to the community that there was a new approach to the care of the dying patient and family.

When we first started, it became pretty obvious to us that hospice was a concept of care, not any pharmacologic or technologic advance, not a new innovative process, but using basic commonsense that our forefathers in medicine used. And this was addressed to the basic comforts such as smooth, clean sheets, back rubs, constipation, diarrhea, pain control, et cetera. In order to do this, the palliative care team had to become preoccupied with the smaller things in life, and it had to start a training program to teach all of us how to manage the little problems that face a terminally ill patient and their family.

It became pretty obvious that we had to become a multidisciplinary team that had to have some knowledge of pain control, such as using morphine mix or hospice mix, rather than more intensive and evasive procedures to relieve discomfort. And much to our amazement, when we began to preoccupy ourselves with trying to relieve the discomfort the patient had, we could relieve their pain in 90 to 95 percent of the time. That is not to say that we did not resort to surgery or neurosurgical procedures or orthopedic procedures. We would trade off several days of surgical discomfort to relieve pain if it was going to relieve it over the next several months.

In some of our patients, when we were trying to relieve pain, it became pretty obvious that pain was not the only problem these patients faced. They also had nausea, vomiting, constipation, and to some of these patients this was more important than pain control. It also became pretty obvious that in some of our patients it was not the pain or the disease that created their problem, but the emotional impact, the anxiety and the pressure that this crisis brought on the patient, and many times we would address this and pain would be relieved without any serious intervention.

In addition, it became pretty obvious that not only was pain control very important but also the problems of the emotional impact the disease had, not only on the patient but also on the family, became very important to us. So not only was the palliative care program directed for symptom control, but also we began to get involved with the emotional impact, the emotional crisis that coping often brings in a person who is about to die. The fear of ultimate separation from friends, family, and loved ones is extremely painful. It became pretty obvious that they needed a lot of backup in order to relieve the isolation and abandonment that the patient's family had.

Moreover, it became pretty obvious when we were rendering care to our patients that not only is symptom control important, not only is emotional control important, but also pastoral care was important. To some patients, dying was more a spiritual process than it was a biological one. For some of these patients, it was more important that their spiritual needs be addressed as opposed to their physical needs. At that time, we begin to incorporate specially trained pastoral care people, religious leaders, ministers, and lay

people who were trained in religion to help us overcome some of the problems that occurred in our patients who were dying.

In addition, it became pretty obvious that the economic impact of cancer on families was an extremely painful burden. Since we had no source of income, we had no source of revenue and many times could not support the various expenses incurred to provide this care to a dying patient and their families. But it was amazing that some of our volunteer programs and many of our volunteers were able to get tires for a family who needed tires for their car, managed to paint a roof or arranged to get a 6-month supply of groceries; and it is amazing that, even though we had no source of revenues, the volunteers in our program could meet some of the needs of these patients.

In addition to meeting the symptom control and meeting the emotional and spiritual needs and socioeconomic impacts that terminal illness had on our patients, it was obvious that we needed to change the attitude of our physicians and our medical care and our community. It became obvious that traditional medicine failed in meeting the needs of many of our patients; and when you walk through the six hospitals of our community, which many times we did, we would still see patients relegated to the back corridors, dark rooms, where rounds were made on them infrequently, writhing in pain and disfigurement, complicated by bed sores and ulcerations. It became obvious that traditional medicine was failing, so we had to embark upon a program that was dedicated to changing the attitudes and changing the current concepts that our physicians in our community had, so we embarked on a program of reeducating our caregivers at the hospital level, the county medical society level, churches, wherever we could get a physician or any caregiver to sit for a moment and listen to our program.

Well, over the ensuing 4½ years, it has not been an easy trip. It has not been an easy road for us to travel because on many occasions we were open to scrutiny, criticized for being somebody weird, somebody who provided a service that was going against tradition. But over the 4½ years, it became obvious that we first introduced morphine mix or hospice mix. Now the community is using this en masse and they are now practicing some of the techniques that our hospice program has initiated. Now there is no doubt that the program has been accepted to a greater degree by the medical community and by the community in general.

Time doesn't permit me to go over the entire paper, but I can tell you that for the past 4½ years this type of program, a caring program rather than a disease-oriented program, is very successful. We have succeeded in achieving our goal and relieving the suffering the patients have from the complications of their disease and relieving it in such a way, with kindness and gentleness and active intervention and not passive euthanasia, not active euthanasia, but good medical practice with kind, gentle, and soft hands of the physician and the volunteers in our program.

In addition we have also met the patient needs and we know the type of impact the disease has on a patient, primarily because of active intervention of our volunteers. In the core of our program has been these volunteers. It initially started with 1 or 2 and now we are up to 60; and volunteers really represent the core of our

program because these are the people, the volunteers being the doctors, nurses, schoolteachers, housewives, survivors of former patients, and clergy that render the care, and they render this full time in the outpatient center or in the home of the patients we care for.

Only recently have we begun an inpatient program, roughly 1 year old, in which a special area of the hospital has been set aside for inpatient care, where patients cannot be managed or cared for in homes or some acute emergency intervenes. This area is not a place to die but only a place for acute care, in an area where we can then control the symptoms or the emotional state of the patient and then they are discharged home. The past 4½ years, the volunteer has been the very successful and very important part of our program, as I have said. And we have cared for greater than 300 patients and their families, and the interesting thing about this is we have done this free of charge. We have not charged one patient 1 penny for that service that is being rendered to the entire community. We continue to hope to do so as the program continues to develop.

Fortunately, although we have been doing this for 4½ years, this is unrealistic in the sense that we can believe that all programs can render this care free of charge. If they want professional services, such as the services of social workers, psychologists, psychiatrists, clergy people, and other types of therapists, we cannot expect it to be done free of charge and without some form of reimbursement.

On the other hand, we cannot expect institutions to fulfill the expense of covering care to these patients. Although our program is free of charge, I am realistic enough to come to the conclusion that it is very important that some form of reimbursement be rendered, as the care is so successful and so important to this segment of our population which has been so long greatly neglected.

I would like to make a pitch along with Phil. I believe that we ought to pressure our Representatives and our Senators to include and pass this bill, S. 1958, to meet the needs of a great segment of our population which has been so vastly neglected.

Thank you.

Senator HEINZ. Dr. Shope, thank you very much. Your prepared statement will be entered into the record at this point.

[The prepared statement of Dr. Shope follows:]

PREPARED STATEMENT OF DR. EARL S. SHOPE

I am Earl S. Shope, medical director of the palliative (hospice) care program located in the Windber Hospital, a 100 bed, small, community health care facility in the suburbs of Johnstown, Pa. The hospital is the smallest of six regional institutions serving a population of approximately 250,000 to 300,000 in Cambria. Somerset, and Bedford Counties.

Current published estimates for 1981 indicate that there were 805,000 new cases of cancer nationwide and 430,000 deaths resulting from the disease. Expressed differently, 1,150 persons nationwide died of cancer each 24 hours or 1 person every 75 seconds. Regionally, 25,000 Pennsylvanians and approximately 900 individuals in the local three-county area died of malignant disease during 1981. It is estimated that one out of four persons will develop cancer during their lifetime. Two out of every three persons who have cancer or 60 percent of these individuals will die of this disease.

Estimates of the direct cost to cancer patients calculated during 1977 (including doctor's fees, drugs, hospital costs, home care, and visiting nurses) totalled approximately $9.1 billion; indirect costs in lost wages, work days, liquidation of tangible assets were approximately $13.7 to $17.1 billion dollars per year.

Experience worldwide for the past 15 to 20 years has recognized and defined the terminally ill patient as an individual with an irreversible progressive disease for which all therapy (surgery, radiation, chemotherapy, or combination), is no longer appropriate; death is the expectation.

Approximately 95 to 98 percent of the terminal illness in the United States results from cancer. Cardiovascular and other degenerative diseases contribute a small percentage of patient deaths.

Moreover, there has been an increasing awareness by the medical profession and society that the traditional therapeutic approaches to the terminally ill have failed to relieve the pain and suffering associated with the dying process.

The universal failure to control symptoms, a lack of specific attention to the psycho-social needs of the patient, and a failure to maintain open, free exchange of information about the death process has been largely responsible for the emergence of the "hospice movement," in an attempt to meet the needs of the dying patient and their families.

In 1971, in the Johnstown area, the palliative care program was established in Windber Hospital to meet the physical, psychological, and spiritual problems of the dying patient. We strive to insure a quality of living that gives meaning to life during terminal illness. To meet the goals of dealing with the complex problems and needs of the dying patients and their families, multiple disciplines were recruited. These included the services of key family member(s), physicians, nurses, social workers, pastoral care persons, psychologists, psychiatrists, dieticians, lawyers, and specially trained volunteers working with the patients.

The goals of the palliative care program were formulated and implemented in cooperation with existing social agencies (i.e., American Cancer Society and Catholic Charities) without unnecessary duplication of services. The palliative care services represent an array of coordinated or collective community services dedicated to the dying patient when active life-saving therapy is no longer being aggressively pursued or deemed appropriate.

The social agencies in the community supplement existing medical and social programs that do not possess the expertise or experience to address the needs of the terminally ill.

The care of the patients and their families has been done largely on an outpatient basis in the home setting. To date, this service has remained free to all recipients in the program.

The hospice care team is charged with identifying the needs of the patient-family unit thus providing direction by which the palliative care program can focus services. The focus of care is: (1) To provide successful management of pain and suffering associated with terminal illness, (2) provide a cheerful environment that will assist a person to live with dignity while dying, (3) to permit persons in the family the right to become involved in the plan of care, (4) to blend the skills of nurses, doctors, clergy, social workers, volunteers, and others who wish to become involved in the care of the dying person, (5) to help surviviors in the grieving process, (6) to demonstrate to the community a new approach to the care of the dying patient and family.

Primarily, the patients are cared for with common sense and basic professional skills directed towards special attention to self-evident problems and physical needs. This special attention to "patient comfort" (clean, smooth, bed sheets; backrubs; frequent position changes; controlled bowels; oral hygiene and freedom from pain) has frequently brought psychological problems of the patient and family into manageable perspective.

The palliative care team's preoccupation with symptom control has required team members to develop special skills in the management of various types of physical distress experienced as a result of the patient's disease. Ongoing seminars have become important in providing the tools to care givers for good symptom control. For example, leading the list of symptoms is physical pain. The pain caused by cancer is varied and can be caused by obstruction, tumor expansion in an organ itself, or nerve compression. In many cases narcotics and adjuvent drugs such as morphine mix or hospice mix taken on a regular basis can successfully manage 90 percent of the patients without resorting to more extensive or invasive procedures. Prior to the palliative care program traditional disease-oriented care has been ineffectual in relieving the pain in the dying patient. At times, cancer victims do require palliative radiation therapy or neurosurgical procedures to control painful

symptoms. The palliative care team is aware that emotional pain frequently contributes to physical distress. Professional counseling in such situations has done more to relieve discomfort than high doses of pharmacologic agents.

For some patients, the control of nausea and vomiting or the relief from diarrhea or constipation has become as important as freedom from pain. Universally, the diagnosis of cancer and/or terminal illness produces a profound psychological impact in the patient-family unit. The palliative care team is acutely aware that dying is as much a psycho-social and spiritual reality as a biologic one. Coping often creates a situation of crisis and depression and is not uncommon in the terminally ill patient. Depression at times results in mal-adaptive behavior, inability to cooperate with care, and difficulty in carrying out life's activities. Fear of ultimate separation from loved ones, family and friends is extremely painful. A sense of abandonment by health professionals, family and friends produces a sense of isolation.

The emotional impact or fear of disfigurement associated with cancer is a difficult problem to resolve and demands skilled, experienced emotional support.

Pastoral care personnel at the Windber Hospital Hospice seek to relate to each patient in creative, comforting, and strengthening ways. It is believed that patients may be frightened by institutionalization, fearful of expressing their own deep and painful feelings, and thwarted in their desire to achieve a rich rapport with friends and family during the darkening days of dying.

With this in mind, each patient is greeted warmly by the spiritual care givers and assured that religious support will be given in accordance with his or her belief and practice. Appropriate community clergy persons are informed of the patient's admission and urged to provide spiritual counseling in keeping with the patient's expectations.

Though volunteers, the chaplains are trained theologians, skilled in the art of listening and counseling, and dedicated to goals of hospice care and to the purpose of quality spiritual support in times of crisis such as terminal illness and death. In their relationship with the sick, they emphasize those elements which promote trust, understanding, and peace of mind. They endeavor to hold at a minimum destructive feelings of hostilities, suspicion, and fear by assisting the patient to discuss untoward elements in his or her thoughts. In other words, the spiritual counselor often may be able to point the way to the eradication of guilt, regret, bitterness, and other hostile feelings and so enable the patient to gain courage to talk about his or her anger toward people and God and thus achieve an inner sense of forgiveness and peace which makes the dying process easier for all involved.

Because of these seemingly obvious benefits, the pastoral care people carry an important role in hospice care, and they continue to build their ministries upon the tried and proven functions of working toward the goals of healing, sustaining, guiding, and reconciling as they join the hospice team in wrestling with contradiction, meaninglessness, frustration, despair, fear, and futility. These feelings are basic to the central elements of religious experience. And the pastoral care people, with the efforts of all members of the health care professions, aid in ministering to human brokenness.

Unlike an acute illness, where recovery is expected, a terminal illness affects every member of the family. Family members primarily carrying the burden of care often suffer extreme anxiety, depression and social malfunction similar to that of the patient. In order to meet the needs of the family caring for the terminally ill, it is important to determine whether the patient is the sole supporter or a peripheral member of the family unit. Family cultural and behavorial patterns, long-term conflicts, and inter-relationships are examined. Identifying and incorporating key family members or friend(s) into the care program provides valuable leadership and frequently leads to successful management of the patient. It is important that nothing be done to separate someone who is dying from his family. The family that shares the moments of difficulty and the desperation and despair of a terminal illness frequently has an enriched human experience. To insure that the death process is not destructive, professional attention by the palliative care team is directed to support the family of the terminally ill during the dying process.

The experience has demonstrated that the terminally ill patients can adequately and comprehensively be cared for in the home setting by key family members. Moreover, measures are initiated to counsel the family (while they are caring for the patient at home) to adjust to living without him. One method involves having key family members assume that functions previously controlled by the patient. In addition, active participation by the family in the patient's care is a self-satisfying contribution to the welfare of the patient. Frequently active involvement averts a feeling of guilt or self-criticism and thus relieves frustrations and helplessness that

97-601 O - 82 - 2

could be detrimental to the healthy emotional disengagement upon eventual loss of a loved one.

Families caring for terminal illness often deny their own needs. This can be adequately addressed with planned, professional counseling directed toward relieving disturbed interpersonal relationships, resolving the problems facing the patient-family unit during the death trajectory.

In the past, death was a family experience. At the moment of death, the family members, friends, and long acquaintances were often present; providing comforting care, exchanging meaningful reminiscences and thus observing the termination of life. Today, death frequently occurs in hospitals and other medical facilities in the absence of family members or friends, attended by only the medical specialists trained to perform technical services to combat disease and death. Today the changing attitudes of our society and the medical profession have resulted in a reawakening to traditional values about dying and death, the values often lost in the highly sophisticated and technologic society. Recent findings have shown that a return to the tradition of dying in the home has been a healthy experience for both the patient and family. This has also been cost effective to our health care system.

After the death of a patient, a bereavement program insures long-term followup of the surviving family members to prevent emotional maladjustment and physical illness.

The palliative care program recognizes that changing attitudes of health care providers is fundamental to the acceptance of the program in the face of standard practices. Not uncommonly with the traditional approach to the terminal illness it is easy to overdo things, to go to extremes to prolong life. Far too often in our medical practice a contest exists between the doctors and the disease of dying with dignity. Although technical ability is important, the attitude of compassion and sympathy by the clinicians is far more successful in relieving the suffering of dying patients.

We have found that there is a changing role of the physician in the palliative care program that includes: (1) Performing the initial medical examination, clinical assessment of the patient and implementation of care protocols that are directed towards palliation of symptoms; (2) medically advising the hospice nurse; (3) availing himself for house calls whenever the hospice nurse deems the medical condition of the patient warrants a physician's special attention; (4) acting as a liaison between the palliative care team and the hospice medical director; (5) directing and coordinating the work of the palliative care team and being available for weekly consultations of the team and medical director; (6) being available for call for families at death if he so desires; (7) maintaining good public relations for palliative care programs and working with the medical director in providing continued education palliative care for peer groups and volunteers.

During the past 4½ years, the palliative care program, through its home care team of specially trained volunteers, physicians, and nurses has rendered care to over 300 patients and their families largely in the home setting. Although this service has been rendered free of charge, it is unrealistic to believe that it can continue over an extended period of time without some form of subsidy. Continuous training and upgrading of care givers has become an important component of the service if quality care is to be insured. There appears to be a tremendous amount of time and hidden expense that is necessary in insuring quality care and protecting the patients and families in our community from suboptimal services.

To address these complex needs, a multidisciplinary team with special skills and training is best suited to solve the problems.

The quality of care provided by the palliative care program as compared with traditional disease-oriented care is currently under study by the social scientists at the University of Pittsburgh. These results are not yet available.

Nonscientific feedback from families, friends, and relatives of departed patients indicate the program has been received with great excitement and enthusiasm. Most of us involved in the palliative care program believe the service being rendered is a unique approach to patient care which has done much to enhance the image of the medical profession and the health care institutions serving the terminally ill in our community.

We believe palliative care is a positive approach to treatment of the dying patient; an approach whose time has come to be incorporated in our general medical practice throughout the Nation.

Senator HEINZ. Dr. Shope, you are a physician and you are uniquely qualified to answer a couple of questions regarding the relationship between the hospice care you provided and other physicians. You have testified very eloquently as to what it meant to the

family, it has meant a great deal to the family. How has what you have been doing affected the relationship between the patient, the physician in charge, and the family physician?

Dr. SHOPE. Senator, we have been very careful to insure that what our care represents is an extension of the primary physician's care, that we represent his arm in a different phase of the patient's illness, and with that in mind many times the primary physician is still called upon to render acute care, still called upon to help manage patients in sort of a partnership. He becomes part of the palliative care multidisciplinary team.

Senator HEINZ. Have you found any resistance from physicians in doing what you are doing?

Dr. SHOPE. I think initially we found some resistance because of the work of asserting an innovative approach to the patient, but during the past several years I think we have been more and more successful.

Senator HEINZ. Now, both of you have mentioned the problems of keeping hospices going based on current reimbursement. Phil Decker explained, quoting Mr. Eisenstat, that hospices would appear to be skating on thin ice and the thin edge of investigation and prosecution by law enforcement people; or just cutting very close to the edge of what is proper and improper in reimbursement. But you have mentioned that so much of what you do, everything you do is free for the patients. My question is, "What is the future of hospices, in your opinion, if we do not reform medicare so that hospice services in some way, shape, or form can be reimbursed or provided for?"

Mr. DECKER. I will start. I really do think, as I feel the strain within Hospice St. John, of which I am the director, as well as seeing, in my travels, other hospice programs are being forced to cut back their services because of the reimbursement system as it is.

I think what we have been trying to do is adapt hospice to fit the present reimbursement system and, again, as it appears in my written testimony, "the round peg in the square hole" type of reimbursement.

What we are doing is taking what is reimbursable from hospice and seeing where it fits, and unfortunately some programs are doing that so extremely well that they are forgetting what hospice actually is. I think the future of hospice in this country, if it is to develop fully as it was intended by people who were so conscientious about providing quality of care, the reimbursement system has to be specifically set up so hospice is a covered benefit.

Also, I feel that programs will begin to close down. This year, I am facing the possibility of laying people off. That means less people will be served, and that is simply because of the lack of adequate reimbursement.

Senator HEINZ. I am not going to ask you to answer this question, but there is something I would appreciate either or both of you or somebody else doing. I do not know to what extent you are familiar with the alcoholism and drug abuse program. It gets at best, mixed reviews. That may be being charitable; and it, of course, started out in many ways similar to the hospice program. For a variety of reasons, you find that you provide a mechanism

for paying for something, people will find a way to take advantage; and I mean providers, a certain kind of provider will find a way to take advantage of that, just to deliver services that may or may not be needed. This happens under medicare all the time.

My question is, "If you could look at that program and compare its problems to the unique potential problems that hospice, assuming that it would be covered under medicare, might run into, how do you deal with those kinds of problems?" I think it would be very valuable to the Finance Committee, on which I also serve, in trying to shape a reimbursement mechanism that would minimize the kind of abuse that has crept into that program.

Now, one of the more technical questions that we are faced with under S. 1958 is how to structure the criteria for eligibility. In particular, there is some disagreement as to whether the criteria for eligibility in hospice should be based on terminal illness diagnosis alone, or whether it should also include a specific prognosis, that is to say, 3 months to live. What criteria would these patients need to have to be eligible for hospice care? Would you care to tackle that first, Phil, and then Earl.

Mr. DECKER. I could speak for Hospice St. John and our admission criteria.

The way we handle the diagnosis and prognosis is, we ask that it at least be a diagnosed terminal illness with a limited life prognosis. We initially began by using a specific 3- or 6-month limit, and we found that there was resistance from patients family members, and physicians to say, "I have *x* number of days to live." Of equal importance in this consideration is that we are not able to predict a prognosis accurately, and should that prognosis be wrong, then often there is some apprehension and anxiety caused within the family and for the patient as well.

Senator HEINZ. I want to be clear on what you said. You are saying that there should be a terminal illness diagnosis and that means that not only should the disease be identified, but the physician should indicate that that disease, based on current medical practice, is a terminal illness. On the other hand, you are saying that the diagnosis should not go farther or specify, in the doctor's best judgment, what the finite prognosis is.

Mr. DECKER. I think, as I said, it should probably be a limited life prognosis, that seems to work.

Senator HEINZ. Well, now, Phil, I am not a doctor. What is the difference between saying to a patient "You have a terminal illness" or saying, "For the purposes of reimbursement there is a terminal illness, and a limited life prognosis?" Is that a distinction without a difference, or is it in fact something different?

Mr. DECKER. Briefly, I would say that the individual and the physician involved are accepting a fact that there is no cure for this disease, but I would refer that to Dr. Shope.

Senator HEINZ. Doctor, would you care to bail us laymen out?

Dr. SHOPE. Well, you know, I agree with Phil that we take the 3- to 6-month timeframe out, for a different reason. One, we found that in working with patients with terminal illness who had a lot of physical symptoms that were not controlled or addressed by the medical community; or the emotional impact was not addressed; or when we did relieve the suffering that went along with the disease;

the patient lived longer. But instead of dying in 2 weeks, for instance, we have one patient that we told the husband she was going to die in 2 weeks, and a year later she is still around. One of the reasons is because of the husband's intense care and preoccupation in keeping this woman moving.

My definition of terminal illness is a patient who has a progressive disease that is irreversible in current medical practice, the patient is going to die of that disease. In particular, cancer, for instance, we cannot tell the speed with which somebody will arrive at death or the duration it takes somebody to arrive at it. It varies from patient to patient. It depends on the particular type of cancer, so clearly the types should be eliminated. The speed and duration is longer in certain patients being cared for in a palliative care program; and, second, patients live longer because of good care.

Senator HEINZ. Another issue is how we should handle, in S. 1958 or any other similar legislation, the question of reimbursement of inpatient care. S. 1958 would really make the hospice responsible for reimbursing a hospital if it was decided that the patient needed to be hospitalized for a brief period of time. There is a cap in the legislation on the extent to which that can be utilized during the course of the event of the hospice, which is a 280-day period in the bill. I gather that poses some problems. Are you prepared to address those problems?

Mr. DECKER. I think that presently the situation is, taking Hospice St. John into account, I have no way of encouraging the facilities for backup hospice inpatient care other than to have them include the extra cost in their acute care reimbursement overhead. I think with the bill in place, the hospice program would be able to reimburse the facility for backup care. In a facility where there are empty beds, it promotes greater utilization of those beds and, if I am not mistaken, I believe medicare pays for those beds when they are empty now anyway.

Senator HEINZ. Somebody pays for them.

Mr. DECKER. Somebody pays for them.

Senator HEINZ. We are not sure how much is paid by medicare or how much by somebody else's health insurance, but somebody pays for those beds.

Mr. DECKER. Somebody pays for those beds, and it would encourage better utilization for those beds. I think another thing that encourages facilities to provide hospice beds is that it would provide and make available a better continuum of care for patients currently in our health care system. Acute care facilities are for people to be cured. Reality is that some people are not cured. People die in this country. By being able to have a hospice patient in a facility and by being able to have that bed reimbursed, as a hospice bed does, enhances the continuum of care philosophy.

Senator HEINZ. Well, with this additional problem, there are four or five really different styles of hospice care.

Mr. DECKER. Yes.

Senator HEINZ. One very successful hospice is one that is a home-based care program, yet even those home-based care programs probably have to have some kind of backup for patient care. And the question, I guess is, "How can we link quality in patient backup care with those home-based programs without encouraging

the building of more inpatient beds?" We already have 50,000-plus beds for the people.

Mr. DECKER. Well, very simply, Hospice St. John is a home care program and as I see it right now, with 70 percent of our patients dying at home, there still are 30 percent that are returning to facilities. When that happens, we lose control over that patient. With the hospice reimbursement in place, we then have something to negotiate with to insure quality hospice care in that system. That is, we, the certified hospices, are going to reimburse the facility for their services.

Senator HEINZ. Now, some hospices have said to us, "Certainly what you have got in your legislation is helpful," but they also express fears that once the patient goes to the hospital, they will lose control, and that the patient will be hospitalized there for too long, and the hospice will end up being billed above and beyond what is really necessary. Is that a fear that you know?

Mr. DECKER. No; it is not because I believe the bill has built into it a system that gives the certified hospice program, the program that is getting reimbursed, the control to evaluate the patient, and they in turn would reimburse the contracting facilities.

Senator HEINZ. That is the way it works—that is quite right.

Mr. DECKER. Then we would have the leverage of controlling the hospice patients' care to make sure the individual is not kept there under the acute care rates or for longer than necessary.

Senator HEINZ. Dr. Shope.

Dr. SHOPE. Well, to answer your question honestly as far as trying to determine what the expenses are that are incurred by a hospice patient admitted to a palliative care or hospice unit, we are in the process of working out those figures. We are doing it just as we have an inpatient facility that has been in existence 1 year and those figures are now being generated as to determine all the expenses that are incurred by that palliative program with those patients. That information is unavailable to me at the present. We are going to see if that figure matches the per diem rate of our institution.

As far as the inpatient facility that we have in our institution, we converted unused beds in a special area of the hospital and remodeled that area to meet the needs of the patients. Those parts were publicly donated by a philanthropic gift by certain individuals in our community, and when you look at that unit, it does not look like a hospital. You walk into it and it looks like you are walking into a living room of your home. There are sofas, rugs, oil paintings, there is a grandfather clock, and the rooms are private rooms that look like you are going into your bedroom. It has its own dining area and kitchen, its own oriental gardens. The initial cost to renovate that area was really through public donations, but the initial cost we have paid for out of hospital funds and would have been roughly $100,000. So what we did was take unused hospital beds in a particular area that could be segregated, and converted that into a hospice facility. This can be done, I am sure, in many institutions around the country where the hospital census is down.

Senator HEINZ. Let me ask you: Do you have any problems with the reimbursement system proposed in S. 1958?

Dr. SHOPE. Our experience has been, in the last year we have been reimbursed for every patient we admitted to our unit. Of the reasons we have been reimbursed: No. 1, we are a pilot program; No. 2, we have been very careful that we placed patients in a palliative care unit that have an acute illness, and we document this and verify it medically. So we have had no difficulty being reimbursed from the present medicare program, because most terminally ill patients do have reasons for admission when they are not controlled at home.

I have not read your bill. I just read your flier, so I am not actually familiar with the wording in it, so I cannot——

Senator HEINZ. Well, if you are not having any problems now, this is not going to add to your problems, I would suspect.

I have a question for Mr. Decker about what Dr. Shope is doing. His is not principally a home-based system, as I gather.

Mr. DECKER. Ours is a home-based system that has been in existence for 3½ years.

Senator HEINZ. Well, here is my question: How does he manage to do this and why is it a problem for you?

Mr. DECKER. How does he manage to have——

Senator HEINZ. He just said he gets most of his costs reimbursed, and you are saying that you are going to go out of business unless you do.

Mr. DECKER. Well, on an inpatient basis—OK—we do not have an inpatient unit.

Senator HEINZ. Well, maybe I misunderstood Dr. Shope. Do you get virtually all of your hospice costs reimbursed one way or another?

Dr. SHOPE. Just inpatient.

Senator HEINZ. Just inpatient. In outpatient, you have a similar problem?

Dr. SHOPE. Yes.

Senator HEINZ. All right, that clears that up. For a moment, I misunderstood you. I thought that you were doing well, you were doing good.

Dr. SHOPE. The outpatient expenses are swallowed. They are free of charge.

Mr. DECKER. I think what I would just like to add to that is if I am not mistaken, Dr. Shope's inpatient costs are all billed under acute care rates, and I think that was part of the problem with hospice programs being initiated and instituted in our acute care facilities.

Senator HEINZ. Very well, gentlemen. Thank you very much. You were outstanding witnesses. We are very appreciative of you being here and of your time. Thank you very much.

Our next panel consists of Bill Luckock, Virginia Siciliano, and Ellen Walton. Ladies and gentlemen, would you please come forward and take your seats.

Bill, I am going to ask you to go first. Let me say how nice it is to see you, and I hope you will give your dad my best.

STATEMENT OF BILL LUCKOCK, PITTSBURGH, PA.

Mr. LUCKOCK. I certainly will. I am quite nervous myself here. I will not read verbatim.

When my wife Nancy first got sick in the winter of 1979, it was quite a while before we realized what it was. In the summer of 1979, we found out that she had oat cell lung cancer. She went through chemotherapy and radiation therapy for the next year. At the end of July, she started getting very ill again. In September, she was admitted to Montefiore Hospital and we were told then that she would be dead within the next few weeks.

At that point in time we were very distressed, how do we go about this, something we do not know how to do. So we explored a few options that were presented to us, one of which was the hospice. I had never heard of the hospice. I had no idea what it was. My wife did. She said it is a place where one goes to die. I envisioned a very cool place. I was very shocked when I went to visit the hospice and talked to the people over there. We went over, or I went over and they showed me a room, a typical room she would stay in. They also showed me the sitting area, the inside, the outside, and I was quite amazed.

At this point in time my wife was very depressed, despondent. We went to the hospice on September 7 and within a very short period of time I noticed a remarkable change in her. She perked up, picked up, and she stayed this way until the end of her life. I attribute a lot of that to the care that people gave to her, just so caring and so loving.

My daughter was taking piano lessons at the time and she is 9 now, but my wife really had not had any opportunity to listen to her play. They have a piano over there. She was allowed to come in and play and see her mom, something she could not do at the hospital, and it made a world of difference. She had her 32d birthday while she was in a week before she died, and the nurses and staff gave her a party, with cake, ice cream, a little bit of wine. It really made a world of difference for her, just to think that someone would do this when you are dying.

When she was in the hospital, she was in a room in the corner at the end of the hall. It just seemed that no one wanted to see her, "Do not remind me of death." The hospice was an entirely different story. It was a very healthy outlook on death and it really helped us a lot. I had the ability to stay with her and help out with her care, and it was an experience that I appreciated, and I cannot imagine how we could have gone elsewhere. I really could not.

Senator HEINZ. That is as eloquent a statement as I think anybody could ever make about how much hospice care means. Bill, it would be hard to relive those months, those years. I am very grateful to you. Is there anything else that you would like to add?

Mr. LUCKOCK. I think that is all.

[The prepared statement of Mr. Luckock follows:]

PREPARED STATEMENT OF BILL LUCKOCK

When my wife Nancy got sick in the winter of 1979, it was thought to be a bronchial condition, but later on it was determined (July 1980) to be oat cell lung cancer. She first went to Dr. Jacobs for treatment and had chemotherapy, radiation therapy and was in the hospital for 2 weeks; then, she went through outpatient chemo clear

through that first year with moderate success. It looked pretty good at first. Toward the end of her illness, in August of 1981, she was sent to Montefiore Hospital and it was determined there that she would never live more than a month. After a week in Montefiore, Dr. Jacobs suggested that we look for other places to be, either at home or elsewhere because there was no more treatment for her. It would have been extremely difficult at home; there is just too much of medication and shots, constant care that she needed. It just couldn't have been done at home. At that point, he suggested the hospice. My wife was aware of what the hospice was, I wasn't. It was her decision to come to the hospice, so we talked it over and everyone was quite satisfied, and here we came.

While she was in the hospice, she was quite content. For the first 2 weeks, she was able to get up and move about—she wasn't confined to her bed, which she really enjoyed—she could go outside in the wheelchair, go throughout the building. The last week, she was confined to her bed, and there the care was just magnificent—there isn't anymore I can say about the care—the nurses were just fantastic. Everyone on the staff were just very caring people, and they would do anything at all day or night, any problems that came up, they were right there to make things easier for Nancy, which made things easier for me.

Nancy and I talked from the beginning of her illness; about how sick she really was. The only thing she didn't know was that in the last few months, exactly how sick she was and how long she would live. By the time she came to the hospice she knew that she only had a few weeks left. When she was in the hospital at Montefiore, she was extremely desponent—fits of depression, crying—and when she arrived at the Forbes Hospice, just the attention that people gave her—that they actually cared and thought of her—changed her attitude entirely.

The depression ceased, rarely did she cry—but she didn't want to go home either—she knew she was dying, and said here is the best place. At one time, she said that she didn't think that it would be a healthy environment for our daughter in the house in the future—how would she feel if her mother had died in the house and she thought she would have tears later on about that. So, being away from the house and yet in an environment where we could come to see her and be with her—that seemed to satisfy Nancy's needs and our 9-year-old daughter Kirstin's needs.

Kirstin knew her mother was sick all along, but not to the extent of her illness. There was some reading material that I was given about death of a parent. I began to talk to her and I think she started to understand what was really happening. We sat down and talked about it one night; I told her that her mother would probably not be coming back home to live with us—that she was extremely ill and she accepted it as much as a child could accept it. I really don't think she became aware of the fact that her mother was actually dead, until quite a while later. We were doing something that normally the three of us would do—I believe we were going to the mountains, and she started crying. We talked about why she was crying, and she told me that she missed her mom, and that was one of the first times that she actually explained to me why she missed her mom, that she was dead, and she was "stuck" with me. She has grown quite a bit since then; she has matured a lot; she accepted the fact that her mother is dead; she goes to the gravesite with me—she is a little bit upset, but not extremely so.

Nancy's father lost his wife to cancer, and he still can't accept Nancy's death through cancer; he still takes it very, very hard. We call each other every 2 weeks, and write letters back and forth. We have been down to see him at least a half dozen times—he is retiring this year, and can spend a lot more time with his granddaughter.

I think I would be in serious financial difficulty if it were not for the hospice. The charge at the hospice was about three-fifths the price of the hospital. She was there for 22 days. There is no way that I could have financially handled the hospital bill. My Blue Cross plan paid for the time in the hospice. If it weren't for the hospice, I would have had to take my wife back to the hospital—there was no other option—towards the end of her life, when she had to be on the oxygen continuously and the shots were coming so close together—the pain was bad—every hour/15 minutes to an hour. There is no way that I could have done this at home, or anywhere else. In the hospital, one of the biggest complaints she had was—when she was in pain, she pushed the buzzer for the nurse, they wouldn't come down—I kept a chart of all her shots—at one time, they were lagging well by a half an hour over the time period—and the shots were spaced pretty well apart—1 hour/2 hours, 3 hours, but I got the impression because she was dying, that they actually didn't want to associate—it's not one of the most pleasant things to be in a room when someone is dying; the apprehensions, or whatever you feel, I do believe that one of the reasons why her medication was not always on time was because of this.

I know that Nancy thought a great deal of this place * * * she talked a lot about it. On her 32nd birthday, she thought just of having her parents in. But her brothers and sisters, uncles, and all of her family and the nurses brought a cake and ice cream in, a little wine and had a party for her. She was extremely pleased; she was even more pleased when everyone left except the staff, and she had some wine with them—she had a pretty good birthday—she really appreciated that.

I know that Nancy thought a great deal of this place * * * she talked a lot about it. The last thing she said was (it was her birthday) that she wanted a TNS unit donated to the hospice—she told me to make sure I do that. She cared for this place * * * the hospice did so much for her, she wanted to do something in return.

Senator HEINZ. Virginia.

STATEMENT OF VIRGINIA SICILIANO, OAKMONT, PA.

Ms. SICILIANO. My story is about my father. He was a widower. We learned in July of 1980 that he had a tumor of the brain which had metastisized from the lungs, and that it was an inoperable tumor, and the doctors at that time gave him a year to live. He was treated with radiation in the summer of that year, then, I believe it was in October 1980, he got a lot worse and was hospitalized. He was quite ill and went through very serious tests and radiation and all kinds of things at the hospital.

At this particular time he was in Shady Side Hospital, and he was quite ill, and later the doctor said he should go home because there was no more they could do for him there. So I took him home to my place. It was Thanksgiving. He came to my house for Thanksgiving. He stayed there 3 days, and he was bedridden the whole time he was there. He could not get up and get around so he wanted to go to his home. We took him to his home and at this time we had gotten involved with the nurses at the hospital on home care. We hired nurses to stay with him around the clock, along with the home care nurses, because he lived with his sister who was 80 years old.

I have seven children. My other sister has three and lives far away, et cetera, so we could not devote to him the 24-hour care that he needed at this particular time. We had a hospital bed at home. He was on oxygen. We got him a portable potty on the first floor. He was quite ill at that time. The home-care nurses came out, at that particular time, once a week or twice a week. Then at Christmastime, my father fired the nurses because he did not like them. The home care—hospice—took over for a time. He was wearing Jobst stockings at that time. They are like a real heavy, heavy pantyhose and he could not put them on himself, and he would not let us girls do it for him, his daughters. So the home care worked out a period of time when they would come out 3 days a week and a volunteer to come out the other days and help him put the stockings on before he got out of bed. They got him up. They would be there at 7:30 every morning to put these stockings on him so he could get up.

He did very well for a period of time, for about 2 months. When June came around he was going downhill. His birthday was in June. He was 72 years old. He celebrated his birthday. The next day my daughter graduated and we celebrated her graduation. From that period on he went downhill very rapidly. The home-care nurses were coming at least once a day, sometimes twice a day. He developed a fever. He needed his medication changed. He was

having trouble eating anything at all. We were having trouble getting anything into him. He became bedridden upstairs. He could not get out of bed. If he did he would fall. My aunt would call me and say, "Ginger, your dad is laying on the floor, you will have to come over and help get him up." So we talked to the nurse at that time and, of course, Dr. Stiller was his doctor and he had suggested, he felt that my father was ready and that he should go into the hospice. I felt that is where he should go. My sister did not. So we had a family conference and discussed it. One of the nurses from the hospice was there this particular day because he was quite ill and I said to her, "Eilene, I think it is time that we really talk to him about this," so she did. She talked to him with us there, that she felt it was time for dad to go into the hospice and the doctor did think that that is where he belonged at this particular time. So he said he was willing if we would take him out occasionally, and I said, "Sure, any time you are capable of getting up and leaving, I will be glad to take you out for an afternoon or whatever."

So we took him in that afternoon. I called and there was a bed available and we took him in that afternoon. That was June 16, I believe, of 1981. My father got out of bed three times at the most from the time that he went into the hospice. He deteriorated very rapidly but yet he hung on. The doctor had said that when he went in he figured a week at the most. He survived 26 days in the hospice. He had the determination to survive. The nurses down there are fantastic. I cannot say enough about them.

What I learned, what my family learned, what my children learned about death is unreal. I have daughters from 9 to 23 years old. They wanted to visit there so frequently because the air there is so beautiful and so homelike, it ended up that my sister and I camped out there. We became hospice regulars and we would have cocktails, a little bit of wine with hors d'oeuvres in the lounge. And the patients and the other families that were there would come out if they were able to, and my father loved it. He just thought this was fantastic, that everybody could be there and he could look out and see them. They would be in his room.

One night we had a party for one of the nurses that was leaving, a farewell party for her, and he was the center of attraction instead of her. It was really—I felt that everyone should make a trip through the hospice just to see the care and the feeling of warmth. It just radiates. It is absolutely fantastic.

As I said, my children learned of death. I have a daughter who is a senior this year, graduating, and they had a lesson on death and dying in religion. She gave her talk and she taught the class. No one had heard about the hospice. No one had heard about dying with dignity. No one had heard about giving a person who is dying love and care and just being there holding their hands, and if they want a drink of water, get them a drink of water, the main thing being able to participate, which we did. We stayed 26 days with my father. We helped the nurses. We wanted to because we knew that these were going to be his last moments and we wanted to be part of that.

Senator HEINZ. Virginia, what would have happened to your father and what would you have done if the hospice alternative had not been available?

Ms. SICILIANO. He would have had to go into the hospital because he could not be taken care of at home. It would have been very sad because we would have certainly missed his last days and being with him and the good times that he gave us and the bad times, too; and we remember the good times. My family and my children would have never been able to be with him. I have a son who came home from college the weekend before my father died and stayed there with him for 2 days and 2 nights and helped the nurses change him, bathe him, move him, and feed him, and absolutely loved it. And to this day he is grateful, because he was not there when he passed away. My two sisters and I were there, and we kind of knew when the end was coming. You learn. I lived through seven deaths in the time my father was there and I kind of thought I was an expert when it was his time, you know, the change in breathing, et cetera, and we stayed with him and we were there, and I am very, very grateful for that. I do not know what I would have done. I would probably have had great guilt feelings if I had not done it.

[The prepared statement of Ms. Siciliano follows:]

PREPARED STATEMENT OF VIRGINIA SICILIANO

My father's problem was diagnosed approximately 1 year before he died. He was being treated for an inner ear problem, which finally was diagnosed as a tumor of the brain, which metastisized from the lungs. It was inoperable, but the doctor said that with treatment, he could probably live 3 to 6 months. So, we started with radiation treatments as an outpatient, and he did fairly well. He lost his hair, naturally, and became a litter fuller through his body and face. He became a little nasty at times and a little jovial at times. Through the summer, he was pretty good then, he had a very bad period. It was October that he really got bad, and we had to take him into the hospital again, and this time, he didn't bounce back like the first time. He was treated in the hospital with radiation and numerous tests were done; it was found that he had blood clots that were forming in the veins, and he had the operation where they insert what they call an umbrella in the vein that collects all the blood clots before it hits the heart. After this procedure was done, he did fairly well, but became very irritable at being in the hospital. He was at Montefiore at that time, under Dr. Stoller and Dr. Jacobs, and at that time, the social worker called and tried to prepare us for what was coming. She said that eventually, it would be a good idea to look in the hospice. We had never heard of the hospice until that time. She said that we could go over any time and go through the unit, and even take my father over if we cared to. At that particular time, most of the family was not ready to admit that this is what should be done, or to say that this would be the best thing to be done.

Dad came out of the hospital and came to my house over Thanksgiving, and he was not capable of doing a lot of things for himself. It was the worst Thanksgiving we ever spent, I think. He was very ill, extremely ill. He left the hospital in a quite agitated mood because he wanted to leave right away, and we had to wait for the portable oxygen tank. He wanted to leave then, and I wouldn't leave with him until the oxygen tank got there. And thank God we waited, because we couldn't walk 10 feet without needing oxygen once we got home. He never got out of bed the whole time he was at my house. I had him down on the first floor, which we made up for him.

I made a big mistake, I bought him a bell. He rang the bell constantly. My children got him anything he wanted. It really was, I think, that he was realizing how sick he was. We took him home, to his own home, and it took my son and my husband to get him into the car. We put a hospital bed on the first floor at his house and got him a portable potty and an oxygen tank. Then we had the problem of someone caring for him. My dad lived with his 80-year-old sister since my mother died. She could not take care of him. He would not let us take care of him the way he should be taken care of because he was a very proud man. And it took a lot out of him for his daughters to see him that way. We called in the hospice home care team at that time. They were very good. I don't know what we would have done without them; their suggestions, their help, phone calls any time of the day or

night. Through the hospice, we located a nursing agency that you can hire nurses through. I thought they worked out very well. We still had the home care from the hospice, and the nurses were doing exactly what needed to be done. He was being bathed, he had to wear Jobst stockings, which he could not get on himself. He would not let any of us help him put them on, he would not get out of bed without them. My aunt was not happy with the situation. She did not want nurses in her home.

There came a point where dad improved so much that we got rid of the hospital bed; he put up his model trains for Christmas. He had a very nice Christmas that year. He was very happy. He went up and down the steps, it was amazing what he was able to do at that particular time. The winter, from Christmas up until April or May, he started going downhill. We could see it. The girls from the hospice could see it. We talked about it. We talked about where he should be. In talking with the nurses from the hospice, we decided that we would leave him at home as long as we possibly could. Then, he started falling. My aunt, as I said, is 80 years old. She could not lift him. I would get a phone call. I live the closest. I would get a phone call at 5 in the morning, "Ginger, your dad fell, and I can't pick him up." So I would have to run over. My husband would have to pick him up and put him back into bed. He started the seizures ending up in bed more and more on the second floor, which meant that my aunt had to make the steps to try and get him something to drink; get some kind of nourishment into him, give him his medication. He became very irritable because he did not want my aunt doing this. He was a very independent person. Since my mother passed away, he felt I guess that nobody should do these things for him.

June 6th was his birthday. He was 72 years old. The next day, I had a graduation party at my house. It was the last good day he had. He walked around like a peacock, enjoying himself thoroughly. He was happy to be with all of his grandchildren, children, all of his musician friends that he had played with years ago. He never, ever, was as good as he was that day again. He started drastically going downhill then, to a point where every other day, he started with fevers and being delirious. One day, after falling, he said to me, "Ginger, you can't lift me," which I knew I couldn't. Fortunately, a nurse lived next door. I ran and got her, and between the two of us, we got him back in bed. That made up my mind for myself that Dad could not stay there any longer. My sister came. She and I discussed it. She did not like the idea of him going to the hospice. It was Eileen, the hospice nurse, that made the visit to the house that time, and I asked her would she please explain the hospice unit to my father. And I sat there in the living room as she did it, and he looked very dejected at first when she started talking about it. He asked his questions, and she told him, "Augie, I think that's where you should be right now, because you are not able to get around as you should." He looked at me, and he said, "when would I have to go?" I looked at Eileen and she said, "I could get you in today. We have a bed for you." My dad looked at me and said, "can I come back home?" I said, sure even if it's just for a visit. Needless to say, it was a very trying day. My aunt was very upset, because she felt that she was pushing him out of her home. But she certainly was not capable of taking care of him. My sister and I brought him down, and he wasn't too happy when he first got in. He looked around, didn't want to get in bed, didn't really want to get undressed. So we stayed with him, and he had his dinner. He finally got his jammies on, and he got into bed. We left and said that we would be back the next day. The home care added up to about 6 months prior to his admission to the hospice.

Dad, I think, deteriorated very quickly once he got here. I think that he was realizing how sick he was, and that he was finally admitting it to himself. He never had talked to us about it though. I think he was only out of bed two times the whole time he was here. One day, he was sitting in the chair outside of his room in the lounge, and another day we got him into a wheelchair, and we pushed him around for a while. During his delirious periods, the nurses had to use restraints to keep him in bed, because he didn't realize what he was doing.

It got to the point where the hospice became a home away from home for my sister Barbara and I, and I know I can speak for her, because we spent a lot of time there. We enjoyed being there, it make it much easier, I think, for all of our children. I have six children that visited there quite frequently, spend the nights there. My sister and I spent quite a few nights there also. We wanted to be with him when he died, and I'm not sorry that I was there. He lasted a lot longer than any doctor thought that he would last. I believe, he had the drive in him to die on the day my mother did, which was July 11. He was in a coma, I think it was 3 or 4 days, and he really did not know us. But, there were many good times at the hospice—the "parties" we had, the glasses of wine. We had dad's homemade wine here, and he had his little sips. The times that my sister and I didn't get to go out and eat, we would

bring things to the hospice, and we would make it like a little cocktail party with the other patients and their families. We became very friendly with quite a few of the patients that were here. We had some real good times, and my father had some real good times. He would play "Name That Tune," lay in bed and hum his songs, and everybody guessing. We'd sit out in the lounge and he'd be laying there and he'd go "pssst," and we'd have to go and see what he wanted.

The nurses all loved him very much, which was quite evident. And, we loved them for the care that they gave him, and what they showed us, and how we learned to accept what we are going through—and, how I learned about death. I sat in the lounge and literally watched six people die before my father, which I am quite thankful for. I watched one person die that didn't have a soul there, which just crushed my heart. I watched other people die that their families were right there with them. We saw one man go home. Dad was surprised that he had gone home. I know, now, that he had gone home to die.

The good times were many, so very many. All my children learned about death in a beautiful way. They knew he was dying; he know he was dying. He finally asked for a priest and had the last rites with my sister and I in the room, which surprised me. He accepted death very beautifully, although I know he didn't want to die. He loved his grandchildren very, very much, and I think his eyes used to twinkle and light up when they'd come in to see him. My oldest son spent two nights there with him. He helped bathe him, he helped turn him, he helped feed him, and he loved every minute of it. He came home from school especially to spend the weekend with him.

I don't know if I can stress enough the importance of a place like this. I would give anything I have for any of the staff here and do everything that I can to help it survive and stay on. And, I hope, God willing, that I will be a volunteer there within the next few months. They said I had to wait a year, and it's almost a year. It is a beautiful place. It's a place that many people should visit, and many people should have the opportunity to be able to come to a place like this—when they can't die at home. If, financially, they cannot afford it, it would be such a crime not to be able to come here. I don't know what we would have done if my father had to stay at home. I know that he would have ended up back in the hospital.

It was different there, because I could go there and I did spend a lot of hours. Then I would go home for a couple of hours, and I was different. I was glad to see my children. I think it is such a beautiful place with the atmosphere so light yet, knowing that there was death there. It was never the dismal feeling that this was it, and that there is nothing more. You learn that death with dignity is beautiful, and I think that's what my father had. In fact, I know that's what he had. And, I will tell you something that I don't say to too many people—after the 23 inpatient days that he had in the hospice, I watched my father die. I knew the last breath he took. I knew what it was, and I will forever be grateful that I did know that. I don't know what more I can say.

Senator HEINZ. Let me ask Ellen Walton, who is a volunteer, to tell us about her career.

STATEMENT OF ELLEN WALTON, VOLUNTEER, FORBES HOSPICE, PITTSBURGH, PA.

Ms. WALTON. My involvement with the hospice came about as a result of my experience when my mother was dying. I was very aware of how important openness and frankness is among all those involved with the care of the terminally ill person, and how difficult it is to achieve that kind of openness. In my case I do not think we ever did and I feel very cheated.

Becoming a volunteer at the Forbes Hospice begins with a 21-hour introductory course covering the theory and philosophy of the hospice, attitudes about death and dying, spiritual needs, physical needs, the concerns of the family when the patient dies, our own attitudes about death and dying, and some of the physical skills that may be needed when caring for a patient.

Our course was for 3 hours two evenings a week, for 3½ weeks. At the end of that time, the volunteers were asked to spend a

month, 4 hours a week during that month, with an experienced volunteer in on-the-job training at the inpatient unit. After that time we are on our own.

Being on your own as a volunteer at the Forbes Hospice can mean a variety of things. It can be helping with a bath, it can be even taking a patient for a ride in a wheelchair for a change of scene, it can be holding someone's hand, it can be listening to someone, to a patient or to the family, it can be playing with children that have come to visit their parents or their mother or their father, whoever is visiting a patient.

Recently, I had an elderly woman who was very close to death who looked at me and said, "Please hold me in your arms." We never really know exactly what is going to be expected or what we can do. We are never expected to do anything that we feel uncomfortable with or that we feel we cannot do; but anything that we feel we can do or could help with, the staff is always going to show us how, and I think have always shown great gratitude for anything that we can help with.

The inpatient unit at Forbes Hospice covers a variety of kinds of patients. Some are there to have their pain brought under control and to be put on some type of routine so that when they go back to their homes they will be able to stay at their homes. Some are there because the families need a little respite in caring for a terminally ill patient. Caring for a patient, no matter how much you want to do it, is a very demanding process and sometimes the family just plain needs a little time off.

Then, of course, there are some who cannot long be managed at home and volunteers will come there to provide hospice care and service. The home care service provided by the hospice is an extraordinary and remarkable thing. Volunteers have participated in that program at the Forbes Hospice after 4 or 5 months of inpatient service at the inpatient unit. Before going into a job as a home care service volunteer, the volunteer home care coordinator will talk to the volunteer and explain exactly what the problems of the patient are and the problems of the family and where the hospice team volunteer can be of more service. Many patients really want to stay home and their families want them to, and because they are provided care by a hospice home care team, this is possible. My home care patient is a perfect example of this.

She is a lovely 82-year-old woman who has always lived with her son but she is reaching a point where her physical needs, such as daily baths, help with changing and washing her appliance, and a urinary incontinence problem are simply too much for her son to do, and so the hospice volunteer care team is able to provide daily nursing and volunteer help for her son.

Maybe the most frequent questions that I am asked are "isn't it depressing" and "how can you stand it." Certainly in situations that occur, the pain and suffering of families and the patient, the loneliness when someone dies, all of these are very sad and affect everybody who is there. But it never could be said that the hospice is depressing. It is staffed by the warmest, most caring, most loving people that I have ever met. The atmosphere is always warm and friendly and everyone is anxious to help. The most amazing thing that I have seen there is that as a patient is dying he or she is

never neglected, never left or put aside, that as long as there is life there is care. There is an attempt to be made more comfortable, to have someone there with you, so that you need not face your last dying hours in any kind of anxiety that can be relieved by someone being there with you. No one is abandoned.

We as volunteers are a great support group among ourselves. We have a regular support group meeting and we need to talk to each other and we do talk to each other. We also get a lot of support from the staff and I think they from us. It is a definite team approach to care for a terminally ill person and I think each of us feels that we do our best for those that we serve and for those of us who are doing the work.

I can only hope that as the word spreads about the hospice concept, it will become a natural way to treat the terminally ill, so that when we do find ourselves in that position, we can expect a dignified way to die.

Senator HEINZ. Ellen, thank you very, very much. I compliment you and all the other volunteers that have discovered in one way or another the hospices around this country, not just here in Pittsburgh, and who have made it possible for hospice to be an alternative. It was not specifically mentioned in the testimony today, but without volunteers, hospices simply could not exist. Part is the reimbursement problem and it is also, I suspect, just a necessity that people who have been through the kind of experience you have gone through within your own family, that you have to a certain extent had preparation before you can deal with the realities in a hospice. So while it may be possible to operate hospices without volunteers at some point in the future, today they are all utterly dependent and totally blessed with people such as yourself, and I think it is wonderful, spectacular what you and others do.

[The prepared statement of Ms. Walton follows:]

PREPARED STATEMENT OF ELLEN WALTON

My interest in the hospice came about as a result of my experience during mother's illness and death. I realized how important it is to have open communication with all people responsible for the care of the terminally ill and how seldom it occurs. I think I felt cheated.

In the idea of the hospice care, each patient and each patient's family is included in the decision concerning his/her care and treatment. The openness of the discussion dealing with progress of the disease and the imminence of death is natural and reassuring.

Home care is the optimum care provided by the hospice team. It is many people's goal to die at home if possible and the family wants this too. It can be wonderful and many patients stay home, if not till the end, at best as long as possible. This would not be possible without hospice home care. My home care patient certainly is an example—she is about 82 and has lived with her unmarried son for all his life. She needed care with bathing, changes of her colostomy appliance, help with a urinary incontinence problem—all four which were just too difficult emotionally for her son to do. The hospice provided daily nursing care and volunteer help which allowed her to stay home.

A wonderful aspect of this is that it is available for patients who need changes for pain control and to get on a routine which makes life at home possible. Also it offers respite for families for whom caring for their loved one at home has gotten to be too difficult and they need a rest. Constant care is very draining and sometimes those responsible just need rest and with the inpatient unit, they know the care is as tender and loving as they could give.

The questions most often asked of me as a volunteer are, "But isn't it depressing?" How can you take it?" Of course, I am sad and the problems facing people are horrendous, but there is nothing depressing about the Forbes Hospice inpatient

unit. There is a warm, caring, loving atmosphere always evident. The one thing that has impressed me most in volunteering is that no one is ever given up on—as life continues, each person is given the care, attention, and love that goes on right till the moment of death. No one is abandoned, and the care and concern spreads to the family also. We all become involved and do whatever needs to be done. For volunteers, this can mean sitting and listening, holding someones hand, I had an elderly woman look at me and say, "please hold me in your arms." Taking one for a wheelchair ride, brushing a patient's teeth, giving baths—just whatever seems to be needed at the moment. We as volunteers feel a part of the whole team—medical, nursing, counseling, and volunteer. I think we are all grateful for the opportunity to be a part of this extraordinary concept. We certainly get much more out of it than we could ever put into it. Let us hope that their concept of caring for the terminally ill will spread and become the way we all may expect to be treated as we face death.

Senator HEINZ. I want to return to Bill Luckock and Virginia Siciliano for a minute and just ask two questions. First, in terms of the services that were provided in the hospice, which were the most important for you? What was the most vital thing? Was it the piano? Was it something else?

Mr. LUCKOCK. There was so much that happened in the hospice that just to pick out a certain incident or something they did for us in particular, it would just be difficult, but the total support—I would have to say the feeling that you are not alone. They make certain that at no time do you get despondent or lose sight of things, and many a time I would go out and sit in the solarium and have coffee and sit with the nurses and staff and volunteers. If you feel down, they try to perk you up a little bit, try to get your mind off what you are going through, the support they give you.

Senator HEINZ. Virginia, is there anything special, any special service?

Ms. SICILIANO. I would think the fact that it is like a home rather than like a hospital, not that it is not sterile, but you know the concept of a hospice, the fact that the girls are in street clothes and not uniforms, and that there is always the kind support.

Senator HEINZ. You are both saying the same thing, the attitude, the approach, the kindness, the understanding, the support. How were each of you included in the decisionmaking at the hospice? Were you involved and consulted in what was done and planned? Bill?

Mr. LUCKOCK. Yes, quite so. I personally lived there for the 22 days my wife was there. I went home for showers and came back.

Senator HEINZ. And who consulted with you? How did the process of consultation occur? Was it through the doctors, the director of the hospice?

Mr. LUCKOCK. I would say most certainly the director of the hospice, the nurses, the individual nurses, basically that was it. The doctor would come in twice a week and check her over, so anything else, other than the change in her medication to relieve the pain a little bit more, basically that was it.

Senator HEINZ. Virginia, did your father have a physician who was treating him?

Ms. SICILIANO. Dr. Stiller was his doctor, the doctor at the hospice there.

Senator HEINZ. And he is the doctor at the hospice, so that worked out very well. You were obviously involved in the decision through that doctor to take your father to the hospice. Was there a continuing process of consultation?

Ms. SICILIANO. Oh, yes, every week that he came in, they would take turns, Dr. Jacobson and Dr. Stiller would take turns coming in and they would just catch us up on how far he had progressed in going downhill, and the changes in medication.

Senator HEINZ. Were there any decisions in which you shared?

Ms. SICILIANO. Not at that particular time. I think the decisions had been made when he took hospice.

Senator HEINZ. Ellen, you described that you had a special training period as a volunteer, a 21-hour course.

Ms. WALTON. Yes.

Senator HEINZ. What was the basic content of the course?

Ms. WALTON. It was done by a variety of people. Madalon Amenta was the first one that we had explaining the concept. I think it is really designed very much to have volunteers get in touch with how they feel about this entire situation. And so it carefully goes through all those things which you will be having to face and having to see, and how you feel about yourself, so you are pretty well prepared by the time you get there.

Senator HEINZ. I happen to have an unfair advantage. I happen to know that you have done a lot of different kinds of volunteer work over the years. How does this differ?

Ms. WALTON. I would say that one of the things that is very evident from a volunteer's point of view is that you are working with professional people all the time, and it really is a team approach. In the Forbes Hospice system, you are a contributing member to each individual case; and I have never been quite so closely involved with the patients.

Senator HEINZ. So you are, in a sense, treated like a professional member of the team; you are assigned to specific inpatients or outpatients, as the case may be; is that correct?

Ms. WALTON. You would be assigned to a specific outpatient, not inpatient, just outpatients, not inpatients, within the unit. I would say any input that we have to give and what we see, or what somebody tells us, or how we do that would be beneficial for the staff to know. And if it helps the patient, it is very important, and I would say yes, we do have quite a bit of input.

Senator HEINZ. So you give as much advice to the team as you take from them?

Ms. WALTON. I would question that.

Senator HEINZ. But whether that is true or not, it is a fact that you do have input and you are not just there to render specific physical services, you are genuinely a part of the team?

Ms. WALTON. Yes.

Senator HEINZ. I think that is something worth emphasizing. I thank all three of you. You have been just extraordinarily eloquent about what to each in your own way a hospice has meant to you, how you learned about hospices, how they create a different environment, and what makes that environment unique. It is really a combination of a team approach that involves the family, you as a volunteer, and the health professions, and you put them all together and it is something very special.

I thank you all for being here. I really appreciate it.

Our next panel is Maryanne Fello, of Forbes Hospice, who just recently was made famous by Ms. Walton's testimony; Frances Cohen, executive director of the South Hills Family Hospice program; Nancy Bohnet, coordinator of the Allegheny Home Care Hospice; and Carol De Moss, nurse clinician, from the Visiting Nurse Association in-home hospice program.

Ladies, thank you for being here, and I will ask Maryanne Fello to begin.

STATEMENT OF MARYANNE FELLO, ASSISTANT EXECUTIVE DIRECTOR, FORBES HOSPICE, PITTSBURGH, PA.

Ms. FELLO. Thank you, Senator Heinz. I feel particularly moved by the testimony that was just given and also will keep my remarks brief because I feel that we have heard quite a bit about the Forbes Hospice from other witnesses.

Senator HEINZ. You are willing to give the others equal time.

Ms. FELLO. Yes, sir. The Forbes Hospice was established in February 1979. Since then we have cared for 465 patients. To begin the hospice program within the Forbes health system, we called on the whole community for support. That support was felt in $280,000 worth of funding from local industry and foundations. We feel quite a bit of responsibility to this community since the investment was indeed substantial.

As we approach our fourth year of operation, we expect an operating loss of $250,000. It is for reimbursement reasons that I feel that the legislation on hospice is so vital, particularly to our program.

A couple of words about the 3 and now going on 4 years that we have been operational. We opened with our inpatient unit and, as I think has been described this morning, the inpatient unit received quite a bit of attention from the media. We realized very quickly that the program was off to a good start. The home care unit, however, in the initial year of our program was not utilized properly because we were known primarily as an inpatient hospice program. We worked in the second and third year to really correct those conceptions and I am happy to say that in the second and third year our length of stay dropped substantially, the first year being 21 days and this year being 12 days average length of stay.

Senator HEINZ. Would you say that again, the average time?

Ms. FELLO. Initially 21 days, the second year was 15 days, and now the third year is 12 days inpatient stay. Our home care program did not start with a bang. We began from scratch. We had really to cultivate our referrals to our home care program and our average caseload in the first year was only 10 patients. Gradually, however, the physicians, social workers, and other agencies in the community realized what extra support the hospice home care program provided. The volunteer service that was described by Ms. Walton, the evening and night visits available from our program to the home, the intensive counseling services are often made and make the difference between readmission to the hospital and a home death.

I would like to point out here that, unlike a terminal hospital admission, the hospice, along with the family, makes treatment deci-

sions based on the patient's wishes and comfort, rather than in an attempt to justify an admission with diagnostic procedures and intravenous preparation and other kinds of testing. Just a word, that also another goal that we certainly have is to try to define the "hospice level" of care. It is not acute care, it is not skilled care, it is certainly not custodial care.

In our home care program, we saw the length of stay increase from 30 days in the first year to 40 in the second, and now to 45 days at home. I would like to highlight a couple of figures. Based on our average length of stay, we can care for a patient roughly for 57 days at a cost of $64.91 a day. Now, you have to remember, though, that this is with an average inpatient stay of 12 days and average stay at home of 45 days.

Senator HEINZ. And that is the average of the two?

Ms. FELLO. Right. Specifically, in the testimony that you heard this morning, Virginia's father was cared for at home for 6 months by the hospice team and this does not include the hired nurses that he hired for $1,388.

Senator HEINZ. The hired nurses were not from Forbes?

Ms. FELLO. No. So Augie got care at home through hospice home care for $1,400. His inpatient admission was $4,800. That was for the 22 to 23 days. So an average for him would be, for 7 months of care, $29.71 a day.

I would like to also point out that inpatient care was not covered under the medicare regulations. Bill Luckock's wife Nancy could not be at home had we not been there for Bill. My hunch is that Nancy would have died in a hospital at a cost of approximately $8,000. We cared for Nancy for $5,400. Again, substantial costs, I agree, but somewhat less than the acute care setting.

Senator HEINZ. Very well. Thank you very much, Maryanne.

[The prepared statement of Ms. Fello follows:]

PREPARED STATEMENT OF MARYANNE FELLO

A. BACKGROUND OF THE FORBES HOSPICE

The Forbes Hospice, a member of the Forbes Health System was established in February 1979. The hospice provides family centered care to the terminally ill utilizing hospice home care, an eight-bed freestanding inpatient unit and a bereavement followup program. In addition to providing a full range of services, the Forbes Hospice also provides a hospice teaching/training component which is available to the tristate area.

The Forbes Hospice is a member of a vertically integrated multi-institutional health care system. As a vertically intergrated system, the Forbes Health System has the opportunity to address health care from a holistic view. It focuses on providing a continuum of care from preventive services (i.e., health education) through acute care or alternatives, such as skilled nursing care and hospice care.

Thoughout its first 3 years of operation, the Forbes Hospice has been plagued financially by a lack of recognition and inadequate reimbursement from third-party payors. This problem has made it necessary to rely on local support and free care from many hospice patients. The Forbes Health System will suffer a $250,000 loss, based on contractual allowances at the hospice for the next fiscal year.

B. PHILOSOPHY

The philosophy underlying the Forbes Hospice emphazies palliative care for the terminally ill within an institutional and/or home setting. Improving the quality of life for the terminally ill is of a major importance in the hospice. In an effort to achieve this end, attention is directed toward:

(1) Treatment of the individual rather than the disease.

(2) Control and/or prevention of pain.

(3) Open communication between patient, staff, and family to assure the patient the opportunity to participate in making decisions regarding the treatment plan.

(4) Efforts to reduce the feeling of isolation by allowing the terminally ill to spend as much time as possible in the home.

(5) Responsiveness to the dignity of mankind by allowing the patient to develop an acceptance style of living while dying.

One major objective of the Forbes Hospice is to provide care for the terminally ill in the home as is possible and appropriate. Readmission to the inpatient unit occurs, however, when the individual's needs can no longer be met at home. The primary purpose of this readmission would be relief of physical discomfort for the terminally ill, or relief of emotional stress for the family.

C. HISTORICAL DEVELOPMENT AND TRENDS

1. Inpatient care

Initially, the major publicity surrounding the Forbes Hospice was directed at the inpatient unit rather than the home care program. This is attributed primarily to the fact that this was the first inpatient unit in Pennsylvania and that the warm, attractive, architecturally unique setting was well received by the public. As a result, most initial patients referred to the hospice utilized the inpatient unit in deference to the home care program. This evidenced by the fact that the average length of stay in the hospice in 1979 was 21.7 days as compared to a projection of 14 days. Another factor contributing to the initial length of stay was the admission criteria which required that all hospice patients be admitted directly to the inpatient unit for evaluation and assessment.

To further its original goal and correct community perceptions, two major steps were taken. An intensive educational effort was made to surrounding hospitals, social service departments and physicians to broaden the knowledge of the full scope of hospice services. Simultaneously, the admission criteria was amended to allow for direct admission to the home care program. The resultant drop in the average length of stay in the second year (15.9 days), and the third year (12.8 days), clearly, indicates the successful, more effective use of the inpatient unit. Clearly the use of the inpatient unit is now approaching its orginal intent, that of a "backup" to the services offered in the patient's own home.

2. In-home services

Hospice home care accepted its first patient on May 6, 1979, 3 months after the opening of the inpatient unit. It received its certification from Pennsylvania State Department of Health as a home health agency in October 1979.

Unlike the inpatient unit, the Forbes Hospice home health program had a gradual beginning. Other hospice home care programs in the area were able to identify candidates for hospice care among their already existing clientele. The Forbes Hospice on the other hand, had no existing clientele from which to cultivate referral sources. The average caseload for home care in the first year was 10 patients.

Gradually, physicians, social workers, and other home health agencies learned that the Forbes Hospice home care program was an ideal referral for a patient/family who would need the extra supports offered by Forbes. Volunteer respite care, evening and night visits, and intensive counseling services were found to often make the difference between a readmission to the hospital and a home death. In addition, the "difficult" or "problem" patient family units were referred when acute care team had "nowhere else to turn." This type of patient would often be supported at home with a short admission to the hospice unit just days before death.

It is important to point out, that unlike a terminal hospital admission, the hospice team along with the family make treatment decisions based on the patients wishes and comfort rather than as an attempt to justify admission with diagnostics, intravenous hydration, etc.

The average length of stay for the Forbes Hospice home care patients has increased from 30 days in 1979 to 40 days in 1980 and 45 days in 1981. Another clear indication of the effectiveness of the program is an increase in the percentage of home deaths from 11.4 percent in 1979 to 24.4 percent in 1980 and 27 percent in 1981. Overall, the Forbes home care team has increased emphasis that has been placed on this component of hospice care.

The Forbes Hospice is continuing to evaluate it's policies and practices in order to provide quality care and support in the most appropriate setting.

3. Bereavement followup

The third component of the hospice program is the bereavement program. This is a formally organized program consisting of a set schedule of contacts: One week after death and then at the 1-, 3-, 6-, 9-, and 12-month anniversaries. All staff involved with bereaved families meet once a month to share experiences and keep abreast of the program.

A file is kept in which the substance of each conversation and indication of need for more frequent contact are documented. Contacts are often via telephone, but home visits are also made. Bereavement workers may have lunch or take a walk with a depressed survivor. Telephone contact consists chiefly of assurances that experiencing sadness, lack of energy, mild social withdrawal are to be expected. Most families cope normally and report concrete milestones—"He's back to work." "She's back to volunteer activity." "I don't particularly want to go out but so's not to hurt my friends * * *"

The Forbes Hospice offers a lecture series and a widowed persons group to bereaved hospice families. This service is also available to the community at large in the future.

Forbes Hospice statistics, May 1982

Total patients	465
Inpatient:	
Average length of stay (days)	12.75
Cost per day	$193.60
Reimbursement (per day):	
Medical assistance	$59.26
Medicare	$91.62
Blue Cross	$66
Paid staff (full-time employees)	12.9
Volunteer hours[1] (February 1979 to May 1982)	9,000
Home care:	
Average length of stay (days)	45
Cost per visit	$60
Reimbursement:	
Medical assistance (per visit)	$13
Medicare (average)	$45
Blue Cross (average)	$45
Referral sources: Physicians and social workers from 22 area hospitals, organizations, and agencies; and family members.	
Patient population (in percent):	
Medicare	44
Medical assistance	10
Blue Cross	24
Free care	9
Self-pay	11
Commercial	2

[1] Or 4.3 full-time employees.

Startup data: Opening date, February 19, 1979; initial funding, $280,000 local industry and foundations; service area, 30-mile radius.

Goals for 1982-83: (1) Work toward adequate reimbursement; (2) increase public awareness of hospice care; (3) increase accessibility of service to hospice candidates; (4) maintain the current high level of volunteerism which is the central core of hospice service; (5) participate at the State and Federal levels in any activity relating to regulations and legislation on hospice services.

Senator HEINZ. Ms. Cohen, you may proceed.

Ms. COHEN. Thank you. It is nice to be here, Senator Heinz, and we are very grateful that the Senate Committee on Aging, under your guidance, is holding this hearing in Pittsburgh today.

Senator HEINZ. Before you proceed, let me just state that I am also a member of the Senate Finance Committee, which is a committee with jurisdiction over legislation, and I am a member of the Health Subcommittee under Senator Durenberger, so we are really killing two birds with one stone. In fact, the Finance Committee is

getting a free ride. We are paying for the hearing and they get the benefits.

STATEMENT OF FRANCES W. COHEN, EXECUTIVE DIRECTOR, SOUTH HILLS FAMILY HOSPICE PROGRAM, PITTSBURGH, PA.

Ms. COHEN. I would like to begin by reading a quote from Sandol Stoddard's book, "The Hospice Movement: A Better Way of Caring for the Dying."

> In medieval times dying persons were seen as prophetic souls, voyagers, and pilgrims valuable to the community in a number of ways, not least in the opportunity they provided those around them for service and spiritual growth. It is a modern and ignorant prejudice to consider death as a failure. It is a modern superstition to avoid knowledge of it, to treat it as if it were something unnatural, shameful or wrong. It is time for us to root out the fears and misconceptions that lie behind this distorted view. We must begin to honor the labor of those pilgrims who journey on before us; in being present for them during the part of their living which is called dying. We must learn better to honor life itself.

This is what the hospice movement is all about. Four years ago, a few concerned individuals in South Hills felt that dying patients wanted to be cared for at home. This dream has evolved into a successful hospice, now in its second year of service to its patients and families.

Months of planning were needed to initiate the pilot project. First, individuals and clergypersons approached the South Hills Interfaith Ministries. They learned that three hospitals had similar ideas, the Mercy Hospital of Pittsburgh, St. Clair Memorial Hospital, and the South Hills Health System. Out of a shared concern came the South Hills Family Hospice Consortium.

Why do we use the word "consortium"? Because each of the four sponsoring members make up the governing body and are devoted to joint programing and planning. The consortium idea is unique. It provides one solid program, with no duplication of service. Each of the hospitals could have set up their own hospice but together they decided to have one stronger program. Each of the consortium members provide advisory and/or support services to the hospice to assure ongoing quality of care.

Our program is not bricks and mortar in the usual sense of a health care provider. It is home, with all the needs and services brought to the patients and the family. It is like the mountain coming to Mohammed. What are the components of the mountain? People, well-trained, skilled, health-care people, volunteer support-care people, and clergypeople, but people is not all. It is what they bring—love, kindness, compassion, a caring helping hand and, above all, a listening ear. A staff of nurses, social workers, home health aides; all provide a comprehensive range of skilled home care services. But in hospice we also help patients reach a feeling of selfworth to live the remainder of their lives to the fullest extent with the least discomfort. This is called pain management or palliative care.

Because of the community-based effort in establishing our program, volunteers are a very integral part. At this time we have 46 trained volunteers. They were trained in three sessions. A fourth session is planned for this summer. We have volunteer nurses which is unique for many hospice programs. Under the direction of

the staff nurse, volunteer nurses provide personal care, respite care, and emotional care. We also have lay or community volunteers, like Ellen Walton. These volunteers develop a rapport with the family. They go into the home and they slowly become a friend and identify specific needs and then meet them. That can be walking the dog, or preparing meals, but mostly companionship and handholding. Perhaps crying together is a big help to the family. Spiritual care is provided by volunteers and clergy. It is a vital link in the health care plan. Bereavement services are also an integral part of hospice care and are available to the family members. Supportive visiting, counseling, and referral to mutual support groups is also available, like these and other groups that help widows. We are developing a widow-to-widow network as part of our bereavement program.

Each week, under the coordination of the hospice medical director, there is an interdisciplinary team conference to discuss the comprehensive care and the care plan for the patient and the family. It is here that I really feel the pulse of the program beats the hardest.

Our hospice is 100 percent home care. If hospitalization is necessary, the patient enters the acute care facility decided upon jointly by their family and the attending physician. Continuity of care is insured by a sharing of information directly by the multidisciplinary teams, and indirectly, through patient information records that are routed along the various channels. Our staff has developed rapport with the specific staffs of individual hospitals. The hospital staff is notified that the patient is part of hospice and prefers to die at home.

After a brief period of hospitalization, the patient then returns to home and hospice care with no real interruption of their direct care information flow and service.

It is difficult to speak for such a limited time about our viable hospice program, and I would be pleased to answer any questions and expand on the testimony. But I would like to end with a note that was sent to us after one of our patients died:

> I could never thank you enough for the kindness in caring for my mother-in-law. She meant so much to me and it really touched my heart, the care that you gave her. What an awful disease cancer is. It is comforting to know that other people like you are willing to battle this enemy shoulder-to-shoulder with the family. Thank you again.

Thank you.

Senator HEINZ. That is a lovely note. Thank you for reading that.

[The prepared statement of Ms. Cohen follows:]

PREPARED STATEMENT OF FRANCES W. COHEN

THE PROGRAM—A SHARED EFFORT

What started out in 1978 as the hope of a few concerned individuals who felt that dying patients wanted to be cared for at home, has evolved into a successful and unique hospice program, now in its second year of service to patients and their families.

It took months of planning and fundraising to initiate the pilot phase of the program. First, interested and concerned individuals and clergypersons approached the South Hills Interfaith Ministries for support. Three area hospitals had begun also to plan to provide specialized care and services to dying cancer patients and their families. Out of this shared concern came the South Hills Family Hospice Consortium

consisting of the Mercy Hospital of Pittsburgh, St. Clair Memorial Hospital, South Hills Health System, and the South Hills Interfaith Ministries. These four sponsors function as a board of directors for the autonomous hospice that focuses its services on care in the home, facilitating admission to a hospital or skilled nursing facility when patient or family need indicates that this is the treatment of choice. Continuity of care wherever the patient may be is insured by a sharing of information directly by multidisciplinary teams and indirectly through patient information records that are routed among the various providers of hospice services. Many patients, after a brief period of hospitalization, for example, may then return to the home and the care of hospice staff with no interruption in their direct care or flow of information.

During its pilot year (November 1980 to October 1981), the South Hills Family Hospice cared for 129 patients, providing both patient and family care and grief and bereavement services. Some patients required comprehensive hospice care services, while others needed only skilled health care services or the support of a trained volunteer.

Having undergone the challenges of the first year as a pilot project, the South Hills Family Hospice Consortium has a program that works and is welcomed by patients and their families. Staff has been increased in order to be able to accept patients needing care who reside within the boundaries of the Southern Allegheny Hospital Association (SACHA).

The South Hills Family Hospice program is not bricks and mortar in the usual sense of a health care provider; it is home, with all the needed care, services and support brought to the patient and family. It's the mountain coming to Mohammed. All the health care and support needed by the dying patient and family is provided in the familiar surroundings of home. Pain and symptom control is a primary focus of the hospice team. Pain is recognized as being emotional as well as physical and both patient and family receive support and counseling from professionals, spiritual caregivers, and supportive visiting volunteers.

A distinguishing feature of hospice care is that it is interdisciplinary and all the team members meet with the medical consultant at a weekly conference to evaluate patient and family needs and to develop a comprehensive plan of care to implement the attending physician's orders.

Patients are referred to hospice by their attending physician when the patient is in the terminal phase of illness and the primary focus of care is pain and symptom relief. Referrals are also accepted from patients, family members, clergypersons, and others concerned about the patient, but care can only be provided upon the basis of a physician request.

Acting as a medical consultant to the family hospice program and a member of its operating committee is Dr. Robert W. Hilberg, chief of division of hematology and oncology, department of medicine, Mercy Hospital. He coordinates patient care conferences and participates in planning and providing staff and volunteer education. He is also available to consult with staff members and the attending physician, when requested. However, the patient's own physician remains responsible for patient care and reviews reports of the patient care team conference discussion. As Dr. Hilberg views it, the goal of the South Hills Family Hospice program is "to maximize the quality of the patient's life when the quantity of life cannot be extended."

Now in its second year, the South Hills Family Hospice program has the capability to accept most patients referred to it from its service area which consists of the South Hills, western Allegheny County, and portions of eastern Allegheny County, including Squirrel Hill. Patients referred from outside of its service area are assisted in obtaining hospice care from another agency serving their community.

In March 1982, a full-time executive director, Frances W. Cohen, was hired. The program looks to a future of even geater service to a growing number of patients and families. A primary goal of the executive director will be to inform the community about the South Hills Family Hospice Consortium and solicit the financial support necessary to provide the additional staff and services needed by an ever increasing group of cancer patients who want to be cared for at home.

While optimum care to patient and family is the primary goal of hospice, one of the most important benefits of the program is that terminally ill patients are enabled to spend their last days of life in their own homes with their own families. The many professionals, volunteers, and others who work together to make it all possible are a wonderful example that the whole world could follow in trying to solve its problems.

THE PROGRAM—COMMUNITY BASED

The community-based effort which led to the establishment of the South Hills Family Hospice Consortium is truly unique. Each of the three participating hospitals (the Mercy Hospital of Pittsburgh, St. Clair Memorial Hospital, South Hills Health System), could have incorporated hospice programs within their establishments. Together, and with the additional support provided by the community based, spiritually oriented South Hills Interfaith Ministries, one viable hospice was formed.

The most cost-efficient modality, hospice home care, was utilized. No facility was built. Resources within the consortium member institutions provided joint planning and programing. Inpatient care, if desired or needed, is available through the consortium members or hospitals. Development funds were granted from local foundations and corporations.

Each consortium member continues to provide inkind advisory and/or support services to assure ongoing quality of care.

HOSPICE HOME CARE

Also unique to our consortium is the South Hills Health System Home Health Agency. The home health agency provides a comprehensive range of home care services in the patient's residence through eight Pittsburgh-area hospitals and our hospice program, including the three consortium member hospitals. These services include professional nursing care, physical, speech, occupational and respiratory therapies, social services, home health aide services, I.V. chemotherapy, lab work, psych-mental health nursing, pharmacy services, medical-surgical supplies and equipment, dietary guidance and home health teaching.

The South Hills Family Hospice patient receives this same coordinated system of care—but goals for our patients vary somewhat. Instead of rehabilitating patients to their fullest potential, team members focus more intently upon providing patients with an opportunity to maintain a feeling of self-worth. This is done by helping them to live the remainder of their lives to the fullest extent possible with pain management. In accordance with hospice philosophy, the patient and family are considered as a single unit of care.

Hospice nurses are especially trained to work not only in an intensive fashion as a skilled hands-on nurse caregiver but also as counselor, a coordinator of help that may be needed, and ultimately as a trusted friend by the patient/family.

THE HOSPICE VOLUNTEER

The role of the volunteer in hospice care is a challenging one. Just as the needs of the Hospice patient and family vary from one day to the next, as well as varying from patient to patient, so do the volunteer's tasks differ. The volunteer is a specially trained companion, a supportive person from the patient's community assigned to help during stressful times, and most important—a friend.

As an integral part of the hospice interdisciplinary team, the volunteer performs and relates in association with other team members—physician, nurse, home health aide, social worker, clergy, etc.—to provide the patient and family with as much (or as little) assistance as they require at any given time.

The volunteers are comprised of three types: lay volunteers, professional volunteers, and office volunteers; the first two are responsible for direct patient and family care. Professional volunteers assist patients with their personal care needs, perform patient care services under the direction of the primary hospice nurse (and ultimately under the attending physician's orders). The volunteer professional often provides respite care for critically ill patients whose family members are exhausted or need to get out of the house for awhile. The professional volunteer also provides emotional support to the patient and family.

Lay volunteers develop a rapport with the patient and family to whom they are assigned and, within the context of that developing relationship, try to meet the identifiable tangible and emotional needs in the home. Sitting with a patient, preparing a meal, babysitting, taking a patient to the doctor, housesitting during a funeral, taking an ambulatory patient out to lunch, doing grocery shopping, or bringing meals are all examples of volunteer endeavors.

In addition to the services offered during the terminal phase of illness, volunteers also provide bereavement followup care to hospice families, which may continue for 6 months to a year following the death of a patient.

Volunteers participate in the weekly patient team conference and interact with other caregiving team members. These volunteers participate in an initial 35-hour

(lay) and 67-hour (professional) training program as well as periodic inservice education seminars.

Office volunteers greatly assist in the operation of the hospice office by helping with typing, mailings, answering telephones, and newsletter distribution. Office volunteers do not participate in the hospice volunteer training program.

SPIRITUAL CARE

The early involvement of the South Hills Interfaith Ministries in the consortium's development has lead to an active spiritual care component in our program.

At the time of a terminal illness, patients sometimes need others to take the initiative in seeking them out. They need visible and tangible evidences of the love, faith, and interests that others in the community have for them. While persons from all religious traditions are enjoined to relieve pain, genuine spiritual care itself must be expressed more in deeds than in words.

Whatever spiritual care service is rendered through hospice, it shall be our goal to love, respect, and honor that personality so that each individual retains his/her personal dignity to the very end.

The patient's clergyperson is encouraged to participate in hospice by visiting the patient and family as well as by attending the weekly interdisciplinary team conference. Active participation by clergy is a goal of our consortium.

SUMMARY

Success of the South Hills Family Hospice Consortium can be attributed to having ready access to the full scope of resources and facilities of three area hospitals accompanied by linkages with community resources and extending all of these in a comprehensive continuum of services to enable each hospice patient to live his life to the fullest in the manner of his choice.

In hospice, traditional treatment-centered modalities are replaced by care directed more toward ensuring patient comfort while maintaining the quality of life as long as possible. When there is even a remote possibility, dying patients prefer to be at home in familiar surrounding with their loved ones. A program such as this affords them an opportunity to do this and assures both the patient and family that qualified staff and appropriate backup support systems are readily available through these multifaceted linkages.

Home care, the primary source of care for any hospice program, has proven through the South Hills Family Hospice Consortium that a coordinated approach of linking three area hospitals with community resources of area ministries and volunteers does provide a highly effective and unique hospice program.

Senator HEINZ. Nancy Bohnet, would you be our next witness.

STATEMENT OF NANCY L. BOHNET, R.N., COORDINATOR, ALLEGHENY HOME CARE HOSPICE, NORTHEAST ALLEGHENY HOME HEALTH AGENCY, PITTSBURGH, PA.

Ms. BOHNET. Yes, Senator. It is a pleasure to be here this morning to talk to you about hospice. I might tell you that planning for our hospice began almost 4 years ago right here at Allegheny General Hospital, which is the regional referral cancer center. They thought that it would be a good idea to add more comprehensive cancer care components, and we started looking at how we could best implement hospice.

They asked me to attend the first national hospice organization meeting. It might interest you to know that that meeting was set up for 300 people. When the meeting finally occurred, they decided to take all comers and 1,200 were in Washington for that particular meeting. We then went to the hospice of Marin as a care-providing team. There was a medical oncologist, a director of home care, I, as a nurse oncologist, and an oncology social worker. We went out there for a residential 7-day training program and came back and reported to the hospice planning committee about what it was we felt hospice was, and how we could best implement it.

Senator, you know that Allegheny General has been building a new hospital in the past few years.

Senator HEINZ. We have all noticed.

Ms. BOHNET. Well, fortunately, we are in it now, but we are in the same situation that we have been for many years, and that is the lack of any excess beds. We are filled to capacity most of the time, so it was not deemed very feasible to try to have any kind of an inpatient hospice if we ever wanted to get it going. So we decided we had a 16-year-old home care program that was intact as part of the hospital, as a matter of fact. It was the home care provider to six hospitals, so, using that as a basis, we started in July of 1979 with a census of 40 terminally ill patients. We provided care to them as their needs dictated on a multidisciplinary basis from the very beginning. We have been able since that time to provide care to 454 patients; 384 of these patients have died, and 63 percent of them this year are now dying at home.

Our first year of operation, the average length of stay was about 32 days. The next year it was 65. It is now 72 days. I think the short average length of stay the first year indicates somewhat of a reluctance to admit patients very early. We deleted a prognosis in numbers of months from the very beginning for admission to the program. We never said how many months. We never said three or six. We just said that it should be a patient that was terminally ill with cancer, his life expectancy could be measured in months rather than in years. Our average charge for a hospice patient, strictly home care, is $1,047, and that is for an average length of stay of 72 days.

The year we started we had a staff of four nurses, and I, as a nurse oncologist, coordinated the program. We now have seven nurses, a home health aide, and we are blessed with 29 trained volunteers and a volunteer coordinator. About 70 percent of our costs are reimbursed by medicare. The rest we have to absorb. We are running quite a high deficit so far in this fiscal year, in excess of $200,000 that the hospital has absorbed for this program, for this year alone. We are not able to get any kind of reimbursement for bereavement, for family counseling, or for nutritional needs for our patients. Bereavement is a vital component of any hospice program. We know that anybody who has had a major loss, within 6 to 18 months after that loss, is subject to either emotional or physical illness. With appropriate bereavement counseling it is hoped that this illness will not occur, because it is a therapeutic way to go through your grief. You come through scarred but healed and healthy.

We have been able to provide most things that at one time were only able to be done in a hospital. We have no restrictions on what we will or will not do. We will give chemotherapy, hyperalimentation, blood work, anything that can be done for a patient within admission to a hospital. We will do it at home.

I think we are very grateful that we have been able to provide this care and hope that in spite of this large deficit that we will be able to continue; and I look forward to July 16 which will be our third anniversary. We are starting our fourth year of care.

Thank you.

Senator HEINZ. Nancy, thank you very much. By the way, I understand that your program, unlike any other program, admits patients without families. Is that right?

Ms. BOHNET. I believe that is something that Carol De Moss will address.

[The prepared statement of Ms. Bohnet follows:]

PREPARED STATEMENT OF NANCY L. BOHNET

ALLEGHENY HOME CARE HOSPICE

Allegheny General Hospital is a 726-bed acute care facility designated as a regional referral cancer center. The hospital is located in Pittsburgh's northside community. There is full utilization of inpatient beds, therefore it was more feasable to develop a hospice program within the existing multihospital based home care program.

The original group of 40 terminally ill cancer patients was gathered from the existing home care census. Interdisciplinary team care was first offered to these patients on July 16, 1979. These patients and those referred for the rest of 1979 required an attending physician from the departments of medical or radiation oncology. They were cared for by a team of four R.N.'s coordinated by a nurse oncologist. The original constraints on referrals enabled the program to learn, grow, and become more refined at a slow, steady rate. Any physician from the AGH staff was entitled to refer patients after January 1, 1980 and from the other five participating hospitals after January 1, 1981. Presently, criteria for admission to hospice is as follows: a diagnosis of cancer, a life expectancy of 6 months or less, a referring physician, and a primary caregiver.

From the onset, care has been provided by an interdisciplinary team including a medical oncologist, social worker, a nutritionist, clergy, psychiatric-mental health nurse, nurse oncologist, registered nurses, and home health aides.

The patient and family are the unit of care on hospice. Visits by care providers have been made on an individual basis as needs dictate, with a primary nurse coordinating care for each patient/family. A full range of services has been provided hospice patients including chemotherapy, IV's, pain and symptom control, physical, speech, and occupational therapies, hyperalimentation, and all skilled and personal nursing services. Emotional support is an optimum consideration for patients and families. Caretakers are facilitated in providing patient care when they are adequately informed about the disease process and treatment regimen. In addition, they need to know that hospice team members will provide them with opportunities for ventilation and understanding regarding their stresses.

The goals of hospice are:

To offer assistance in helping patients, families, and health care workers improve the quality of life.

To help the patient make choices regarding his own care and symptom control.

To treat symptoms such as pain, nausea, and anxiety with the most current and best methods available.

To facilitate communication between the patient, his family, and caregivers.

To support the family during bereavement for at least 1 year.

Care has been provided to hospice patient/families for almost 3 years, ever mindful of these goals.

Twenty-four hour coverage is provided by hospice through the hospital switchboard paging operation. Hospice nurses are available 24 hours a day, 7 days a week, primarily by telephone at night.

Bereavement followup is an essential component of hospice. Since it is not reimbursable, visits must be absorbed by the program. The initial visit following death is usually at the funeral home during visitation hours. Families are then followed, primarily by telephone, on a monthly basis. The regular contact from the hospice team member provides the survivor with the opportunity to deal with his grief in a therapeutic manner. The person responsible for bereavement followup understands that grief has predictable stages: shock, mourning, and a period of adjustment. Survivors do not move through these phases in an orderly manner nor in a set timespan, but the usual grieving process lasts for from 1 to 2 years. Reassurance is offered families about the care they gave the patient in his final days. Family members share their feelings about illness, death, thereby expressing their grief. The person doing bereavement counseling will listen to the full range of emotions without judgment or criticism, praises the caregiver for his efforts, and comforts as necessary. The normal grieving process enables the survivor to continue living, scarred but healed.

The abnormal grief process may result in suicide, withdrawal, alcoholism, or drug dependency. Those doing followup are aware of appropriate referral sources and utilize them accordingly when grief appears abnormal.

Acceptance of hospice as a valid concept can be seen by ever increasing referrals, staff satisfaction, thank you letters, family evaluation, and financial contributions to the program. Another indicator is the number of applicants wishing to become volunteers. Hospice volunteers are both men and women, all ages (minimum 18) and from all walks of life. They are recruited, screened, trained in an eight-session series of classes, supervised and supported by the volunteer coordinator with team assistance. The volunteers bring much to hospice and round out the services available to patient/families. They offer companionship to patients, respite for caregivers, support and assistance to the team. Volunteers are also used to assist with bereavement, fund raising, newsletter, and clerical work. Their services run the full gamut of aid and assistance for hospice.

Allegheny Home Care Hospice has provided care to 454 patients, 384 of whom have died. The census remains stable at 40 to 45 patient/families cared for by a staff of seven nurses, a home health aide, social services, other disciplines as needed, and a cadre of volunteers. The average length of stay present is 72 days. The average charges per patient: $1,047.

The experiences of our years of providing care have led to several discoveries. First, there is no one right way to provide hospice care. There are many models for hospice, all appropriate if they meet the needs of the patient, family, health care providers, setting, and the community. Second, a hospice must be flexible and innovative, open to new ideas and never satisfied with the status quo. Third, a hospice program should acknowledge that patient/families provide their motivation for existence. As we continue to learn and grow, we recognize that our patients, families, volunteers, and coworkers have all been inspirational. We shall strive to continue providing high quality interdisciplinary care. We are grateful to those who have helped foster our development over the past years.

Senator HEINZ. Carol, you are next.

STATEMENT OF CAROL J. De MOSS, R.N., M.N., C.S., NURSE CLINICIAN, IN-HOME HOSPICE SERVICE, VISITING NURSE ASSOCIATION OF ALLEGHENY COUNTY, PITTSBURGH, PA.

Ms. DE MOSS. The Visiting Nurse Association has offered an in-home hospice care service which began in the community in September 1979. We started the service after the staff expressed a desire to more fully enhance and preserve the quality of life for the person who is dying as well as for the family and other loved ones. Following an assessment of community need and support by our administration, the hospice planning committee was established. This planning committee was multidisciplinary and included staff nurses, a registered dietitian, a speech pathologist, a physical therapist, social workers, and oncology clinicians.

After the 6-month planning and development period, the in-home hospice service was initiated. Our initial patients were drawn, for the most part, from our existing home care caseload. Approximately 300 primary patients and their families are served each year by the health team that includes nine full-time registered nurses, two social workers, a pastoral care counselor, a nurse clinician, a nurse program coordinator, and six home health aides. We also have two registered dietitians that provide in-home visitation 2 days a week. In addition, we have speech pathologists, physical therapists, and occupational therapists who are available for consultation and visitation as necessary. Medical supervision for our program is provided by the patient's own personal physician.

We have a small corps of volunteers which includes our full-time pastoral counselor. They are, of course, included in the health team. The key individuals, who are the most important part of the

team, are the patient and their loved ones. There is no arrangement in our program for inpatient respite care. In-home respite care is made available by 8- to 24-hour placements of home health aides from our program.

Anyone can refer to our hospice service, patients are referred from hospitals, from other home health agencies, private physicians, or patients and clients themselves. There are no restrictions such as age, diagnosis, or inability to pay. The ages range from 1 month to 100 years of age. That is about as far a range as you could find. It is not unusual to have children or young adults, but 60 percent of our patients are medicare. Patients with any terminal illness are accepted. About 95 percent of our patients have cancer, but we also take patients with chronic obstructive lung disease, cardiac disease, and some degenerative neurological diseases, which are unaccepted diagnoses for most hospice programs.

In-home bereavement counseling, which continues after the patient's death, is an integral part of our program. We are available to provide in-home counseling primarily because of the United Way money, since we are a United Way agency. A bereavement group was started in December 1981, and meets monthly and is run primarily by our staff volunteers.

Presently, funding is provided by third-party payers, such as Blue Cross, medicare, medicaid, and some private insurance companies. Medicaid pays approximately one-third of the cost of a visit. United Way moneys are used when the client is uninsured and unable to meet the cost of care. A separate patient fund has been established from memorial contributions. These funds are not used to meet operating costs but purely for the needs of patients. This fund has been used for various needs, such as providing additional respite care for the family, the purchase of food supplements or medications, ambulance transportation, or anything else that patient happens to need.

Much of our hospice service, like other hospice services, is not reimbursable. Pastoral care, caretaker relief, in-home respite care, nutrition counseling, bereavement counseling, and time spent in teaching and guiding the family and significant others are examples of uncovered expenses.

Senator HEINZ. Thank you very much.

[The prepared statement of Ms. De Moss follows:]

PREPARED STATEMENT OF CAROL J. DE MOSS

The Visiting Nurse Association of Allegheny County (VNA) is a voluntary, nonprofit United Way agency established in 1919. Our primary purpose is the delivery of health and health related services to residents of the county who are homebound by virtue of illness or injury.

Since September 1979, the VNA has offered in-home hospice care. The service was begun after VNA staff expressed a desire to more fully enhance and preserve the quality of life for the person who is dying as well as family members and loved ones. Following assessment of community need and support by administration, a hospice planning committee was established. The committee included the associate director, nurse clinicians, nurse program coordinators, staff nurses, social workers, a registered dietitian, a physical therapist, and a speech pathologist. Following a 6-month planning and development period the in-home hospice service was initiated. The service is available 24 hours a day, 7 days a week to provide the care and support necessary to make the last months of life as tranquil and dignified as possible.

An initial group of patients, staff, supplies and equipment, and the funds to support this effort were diverted from the budget of VNA's generalized care of the sick

program. Ongoing funding requirements for hospice were built into succeeding operating budgets and the deficit is supported by United Way of Allegheny County. Operating expenses for the first full year of service, 1980, were $300,000.

Approximately 300 primary clients plus their families are served each year by a health team which includes nine registered nurses, two social workers, a pastoral care counselor, a nurse clinician (oncology clinical specialist), a nurse program coordinator, and six home health aides. Two registered dietitians provide direct care 2 days a week. Speech pathologists, physical therapists, and occupational therapists are not assigned specifically to the hospice but are available as needed for consultation and/or direct service. Medical supervision is provided by the client's personal physician. Volunteer service is provided by a small group of individuals and includes the full-time pastoral care counselor. Ancillary staff includes a full-time clerk for clerical and secretarial duties. The patient and his family/loved ones complete the team.

There is no arrangement for inpatient respite care. In-home respite care is made available by 8- to 24-hour home health aide placements. Patients are admitted to acute care facilities or skilled nursing facilities as indicated for medical care.

Anyone may refer to the hospice service. Referrals are received from many sources and include hospitals, private physicians, other health care providers, VNA care of sick staff and patients and family members. The average length of stay on the program is 112 days. There are no restrictions as to age, diagnosis, or ability to pay. The age of the primary patient has ranged from 1 month to 100 years of age. Approximately 60 percent are medicare eligible. Although patients with any terminal illness are accepted on the program, about 95 percent have cancer. Over 10,000 visits were made in 1981.

In-home bereavement counseling, which continues after the patient's death, is an integral part of the program. This service is available primarily because of existing United Way moneys. A bereavement group was started in December 1981 and meets monthly.

Inservice for staff is considered a vital part of the program and is provided on a continuing basis both within the agency and outside the agency, as least monthly. The Fruit and Flower Mission, a VNA benefactor, has contributed funds to permit the special education outside the agency. This money also pays for the services of a faculty person from the University of Pittsburgh who acts as the facilitator for a support group for hospice professional staff.

Presently, funding is provided by third-party payors, i.e., Blue Cross, medicare, medicaid, and some private insurance companies. Medicaid pays approximately one-third of the cost of a visit. United Way moneys are used when the client is uninsured and unable to meet the cost of care. A separate patient fund has been established from memorial contributions. These funds are not used to meet operating costs but are designated for specific patient needs such as purchase of medications and food supplements payment of utility bills and ambulance transportation, and supplementary respite care and rental or purchase of hospital equipment.

Much of hospice service is not reimbursable. Pastoral care, caretaker relief, in-home respite care, nutrition counseling, bereavement counseling, and time spent in teaching and guiding the family/significant others are examples of uncovered expenses. Without legislation to correct the deficits or additional support from other funding, i.e., United Way, or corporate moneys, hospice care for most programs will not meet necessary standards.

ADDENDUM

VNA's in-home hospice service averages 69 visits per medicare beneficiary served. The primary patient receives 51 visits and 18 visits are provided to the family/loved ones. Medicare reimburses 98 percent of the visits to the patient and does not cover any service to the family/loved ones. Considering all service provided on behalf of the medicare beneficiary, 72.5 percent is covered and 27.5 percent is not covered.

Senator HEINZ. Now, as I understand it, volunteers play a role in each of your programs. Is that right?

[All panel members answered "yes."]

Ms. DE MOSS. Ours is a smaller part.

Senator HEINZ. A smaller part in your case. Now, I know Forbes. We have heard all about Forbes from Ms. Walton today, who has a 21-hour training program. What kind of training do the rest of you have?

Ms. COHEN. We have a very extensive training program. Ours is a little longer. Our lay or community volunteers have a 35-hour training program, and the nurses who volunteer their skills have an additional 26 hours. The course includes lectures, readings, films, tapes, group discussions, and role playing.

We also provide a support group for volunteers. Volunteers gather once a month to discuss their problems and concerns. Our volunteers also participate actively in the team conference, discussing the patients. Our volunteers are neighbors from the community in which our patients live. We, therefore, recruit our volunteers from specific communities and have found that the Pittsburgh Press "Helping Hand" request for volunteers, which appears every Sunday, is useful. We just advertised for volunteers from McKees Rocks, Homestead, South Side, Clairton, and Munhall and received about 70 responses. We, therefore, will hold another volunteer training program this summer.

Senator HEINZ. Did all of you out there hear that? Nancy?

Ms. BOHNET. Yes, we have a 24-hour volunteer training program. One of the exciting things about this whole hospice concept, and especially involving volunteers, is this is an area where we get men; and we have men who range from being retired and interested to being professors at the University of Pittsburgh. So we run a full age range. We require that somebody be 18, no maximum, no particular background, just a thorough screening, and continuing education and support group is also mandatory. They meet once a week for the training program itself. Since our program deals exclusively with cancer patients, we tell the volunteers what cancer is and is not, how the treatment modalities work, how to deal with pain. The big focus of the program is on communication skills and in dealing with your feelings around loss.

Senator HEINZ. Carol, although you use volunteers a bit less, you still have some, do you not?

Ms. DE MOSS. Yes.

Senator HEINZ. Do you train them?

Ms. DE MOSS. Yes. Since we do have such a small corps, we have no set length of time for the orientation, but there is a 2-day orientation to our organization, their responsibilities, and the program. Beyond that it is on-the-job training.

Senator HEINZ. Well, the reason I asked all of you this question is that there is an assumption that volunteers are free. First of all, let me make it very clear that you invest rather heavily in training them. How can you estimate the cost of volunteers? Clearly, without the volunteers you could not operate. You have given us some numbers, let us say $20 a day is the average over a 6- or 7- month period. I think it is an arbitrary number. What portion of that $20 probably represents the investment that you make in volunteers, $3, $4?

Ms. COHEN. I would like to say that we all have to pay a volunteer coordinator and the accompanying clerical staff. That is the major cost. We do receive some contributions for our training program. Our volunteer program cost is in the range of $30,000 to $40,000 a year.

Senator HEINZ. What percent of all your outpatient costs would that be?

Ms. COHEN. Our program is still new and our staffs are paid by different members of our consortium. I do not have total figures at this time.

Senator HEINZ. Would anybody have a feel for the percentage of outpatient costs attributable to the volunteers' training and coordination: 10, 50 percent?

Ms. FELLO. I can say, Senator, that to train and operate our volunteer program costs us about $25,000 a year, so that is about 10 percent.

Senator HEINZ. Does anybody reimburse you for that?

[All panel members said "no."]

Ms. FELLO. But the savings, I just wanted to add, we are looking at a figure of about 90,000 volunteer hours, and that is a savings to us of roughly $50,000 in manpower, so it is considerable.

Senator HEINZ. It would be very considerable, I am sure. Now, some of you have given some statistics on the average stay in the hospice program. The average stay in the entire program nationwide, I am told, ranges from 40 to 60 days. Now, I think it was Nancy who said that her stay had increased to 72 days. What are the average stays in your programs?

Ms. COHEN. Ours, for the first year, was 43 days and now it is about 49 days.

Ms. DE MOSS. About 112 days.

Ms. FELLO. 57 days.

Senator HEINZ. There is quite a variation. Why is there such a variation? Carol, yours is almost twice as long.

Ms. DE MOSS. We actively look for patients earlier, I think is one part of it. We get a lot of referrals from patients' families, as well as some cases from our own home care program. We recognize that patients and families need help before the last 3 to 4 weeks of life, so we are very happy with that figure.

Senator HEINZ. One question that would come up on this legislation is, if we pass the legislation which allows 180 days of reimbursement and respite care, will we not invite everybody, instead of providing 57 days or 112 days, to go to 179 days? What answer do you give the critic of the legislation who says that by reimbursing up to 180 days an episode you give an incentive for everybody to go out and put more people on the program for longer? What is the answer to that question?

Ms. FELLO. The goal of any hospice program is as much time spent at home as possible. Our inpatient, when viewed correctly, is a backup of the home service, is under the same scrutiny as the utilization review policy that governs hospital and skilled nursing centers. So that I certainly think, in the development of standards it is a necessary part in this process of legitimizing hospice, that the utilization review techniques are really the watchdogs for the program.

Senator HEINZ. Has your average length of stay lengthened each year?

Ms. FELLO. Inpatient care or total?

Senator HEINZ. Total.

Ms. FELLO. It has been about the same.

Senator HEINZ. Because your inpatient has shortened?

Ms. FELLO. Right.

Senator HEINZ. And I was waiting for the answer. I did not get it. Well, maybe as the people stay on the programs longer the inpatient stay shortens.

Ms. COHEN. It could be. I think also that as the program becomes more popular and more people understand what hospice is, more families will begin to think "hospice." Also, more physicians will be willing to refer their patients to hospice as they see the movement become successful and helpful.

Senator HEINZ. Do you know the history of your inpatients? Do you have an update on your inpatients?

Ms. COHEN. About 50 percent of our patients do go into the hospital at some time during their stay with us. It is hard to give you an average, but the range is about 3 to 7 days normally. There are some that stay longer and some that go in thinking it will be for 1 day or 2 and then they deteriorate immediately and die, but 3 to 7 days is usually the inpatient stay.

Senator HEINZ. Nancy, what about your stay?

Ms. BOHNET. We took a look at this year's patients and how many of them did go into the hospital, and 58 percent of the patients admitted to the program this year went in, which means that 42 percent, from the time they were admitted to the program until death, never went back to the hospital. Of the 58 percent admitted, their average period of stay out of that 72 days is 17 days.

Senator HEINZ. Seventeen. Maryanne, just to come back to you for a minute, on the 21, 15, and 12 days, was that just for the group that was hospitalized or is that the average for all?

Ms. FELLO. Well, I speak of inpatient, Senator. I am talking about hospice inpatients.

Senator HEINZ. Hospice inpatients. OK.

Ms. BOHNET. Although we do refer to Forbes Hospice, that inpatient stay would be about 17 days, if the patient did go away from home.

Senator HEINZ. Carol, what are your statistics?

Ms. DE MOSS. We took a random survey because we do not keep actual statistics. We found that 40 percent of our patients did not go back into the hospital at all during the average 112-day stay. Looking at the other patients, they ranged from a hospital stay of 2 days, when going in for chemotherapy, up to one patient who was admitted for 56 days with a fractured hip, who had surgery and additional complications. It is pretty hard to pinpoint an average, but our estimate is 12.9 percent of the time is spent in the hospital or other health facility.

Senator HEINZ. One question: Since hospice is principally a home-care program, the one question I wonder about is, when a patient does have to go in for acute care in the hospital, how do you manage the continuity of that care? Is that difficult or is it easy?

Ms. DE MOSS. It is difficult. We make attempts to do it and I think in some cases we do accomplish continuity of care, but it is a difficult issue because we really do not have any control. One of the things that we do, of course, is try to improve the communications, by making certain that we notify the physician, as well as the nurses and the social workers in the hospital, exactly what happened in this patient's home, how they have been coping and what were the major problems. In some instances we feel we have

been very successful, but not as successful as if we had complete control.

Senator HEINZ. What are the basic reasons that the patient needs hospitalization?

Ms. BOHNET. A lot of our patients are subject to the complications of cancer, one of which is hypercalcemia. This can be better managed in the hospital.

Senator HEINZ. Would that require intensive treatment?

Ms. BOHNET. Yes, it does. It could be done at home but we have never successfully managed anyone at home with hypercalcemia. The calcium level is very high and it is better to bring the patient in, even if it is for 3 or 4 days. Some patients are still on palliative chemotherapy that is best done in the hospital for the same reasons. Some of these drugs need to be very closely monitored and are still best given in the hospital rather than at home. We are going to give that a try sometime this year. Some patients can be made to feel a lot better if they have a transfusion. If their red count goes down, they are very fatigued. They can be made to feel much better with a unit or two of blood. This is another procedure under discussion right now. Some States are doing transfusions in the home.

Senator HEINZ. Is that about the same for all of you?

[All members of the panel answered "yes."]

Ms. DE MOSS. I agree that in some cases patients must be admitted for care in an acute facility, but we have had some success in controlling hypercalcemia at home with intravenous drugs, and are able to give almost any chemotherapy drug at home. Both of these advances, and the likelihood we will begin giving transfusions in the home, further decrease the need for hospitalization.

Senator HEINZ. The first panel described some of the problems and you touched on some of them. At least half of your patients I gather are medicare-eligible patients. Would you supply us—and I would ask each of you in turn to supply us with a record of the followup review and the average cost for a patient in your program, and percentage of those costs covered by medicare. From what I have heard, I gather you are fortunate if 70 percent of those costs are covered. Would that be about right?

Ms. FELLO. That would not be for the Forbes program, but I think again you are looking at patient care and home care.

Senator HEINZ. I am thinking of the home care, the outpatient care in the home. What portion would you say is covered?

Ms. FELLO. I would say about 70 percent.

Senator HEINZ. About 70 percent. That was my feeling. And I guess some people would say 70 percent, that is better than two-thirds of your costs, that is terrific. What happens to you eventually if only 70 percent of your costs are reimbursed?

Ms. BOHNET. I think that maybe the finance department would decide that maybe Forbes and the other hospitals should take over hospice care.

Senator HEINZ. What are the principal things that are not reimbursed?

Ms. COHEN. Well, certainly administration and supervision of volunteers are enormous items that are not reimbursed.

Senator HEINZ. What about palliative outpatient care, that is not reimbursed?

Ms. BOHNET. No.

Senator HEINZ. That is not reimbursed?

Ms. DE MOSS. Nor is nutritional counseling or bereavement counseling.

Senator HEINZ. Is there any counseling that is reimbursed here?

Ms. BOHNET. Directly to the patient.

Senator HEINZ. By——

Ms. FELLO. An MSW.

Senator HEINZ. By what?

Ms. FELLO. By a MSW masters in social work.

Senator HEINZ. And nurse counseling?

Ms. FELLO. Yes.

Senator HEINZ. Do any of you charge the patient for those unreimbursed services?

[All members of the panel answered "no."]

Senator HEINZ. No?

[All members of the panel answered "no."]

Senator HEINZ. Now I gather, Maryanne, you use skilled nursing-home beds in your inpatient program?

Ms. FELLO. That is right.

Senator HEINZ. Do you have any—this is a loaded question, and I know the answer before I ask it. I have a bill to do something about it, S. 1754, but let us keep the record straight. What reimbursement problems do you encounter because of this?

Ms. FELLO. I am so glad you asked that. The Forbes Hospice does utilize a license for skilled nursing. We are licensed to provide skilled nursing care for our hospice beds. One of the most striking dimensions of medicare are the actual regulations that govern skilled care.

In Ginger Siciliano's father's case, medicare did not recognize his admission to the hospice because Ginger and her sister and the hospice team had kept him home longer than 30 days post-discharge from the hospital, so that 30-day restriction for admission is quite limiting.

Senator HEINZ. So if you do a good job in caring for someone at home, you lose eligibility for your nursing care?

Ms. FELLO. Exactly.

Senator HEINZ. That is a terrible—that is a pretty dumb message for Washington, D.C. to send, but I suppose it is not the only dumb one.

Ms. FELLO. It is a very common occurrence. The other dimension in the medicare regulations which restrict us very severely is the way that medicare defines what is called skilled nursing care. To highlight, a patient coming in to the hospice unit with intervenous hydration, who decides, "Enough of the tubes, I do not want any more IV's," is also jeopardizing his medicare coverage for that admission. So at the point he is saying, "No, no heroics, I am beginning to understand what is happening," he is also in danger of losing a reimbursement for his stay there and that is a doubledged sword that is very hard to deal with.

Senator HEINZ. What about the 3-day prior hospitalization requirement under medicare to be reimbursable for skilled nursing health care, is that a problem too?

Ms. FELLO. We have lost several patients who had been out of the hospital more than 30 days and we were aware of this in advance and said, "The hospice unit would take you but we have to work out another means of payment. If you go to the hospital for 3 days they will pay for your admission to the hospice." We have lost patients because they have opted to go the hospital route and have died in the hospital.

Senator HEINZ. Is that because people down at HCFA, the Health Care Financing Administration people, feel that there is only going to be proper utilization review if you take someone through the open arms of the hospital? Is that your understanding of the rationale of that 3-day stay?

Ms. FELLO. Sometimes it is hard to understand the rationale of HCFA, but my best guess would be that that 3-day admission was meant to allow an acute care evaluation of that patient. That evaluation, though, is something that we have the capabilities of doing in the hospice.

Senator HEINZ. I think maybe that is the right answer. Whether it is review or evaluation, the health care system in this country is dynamic, as evidenced by the growth of hospices and the ability of hospices to do these things. We kind of have this mental fixation, at least we have had it since 1965, that things can only be hospital based to be valid, but that is changing, we are approaching health care from other providers. Hospices are not presently certified and there are many different types of hospices. Each of you represent different types. And I understand, Ms. Bohnet, you have been working with the Joint Commission on the Accreditation of Hospitals to develop standards which could be used for certification. Do you think it is going to be possible to have one set of standards for hospices, given the different models that currently exist?

Ms. BOHNET. Yes, and I think that if the standards were not written in any other way, it would be detrimental to hospices if they were written to cover only, say, home care or only to cover inpatient. And there are probably six models in operation right now in this country.

Senator HEINZ. Why do you think standards are needed?

Ms. BOHNET. Very simply, quality of care; quality assurance.

Senator HEINZ. Now you realize that there are all kinds of advantages to quality assurance and there are all kinds of disadvantages. One of the disadvantages is that you have people like HCFA and others writing very complicated regulations. There are all kinds of redtape. We have had a tremendous amount of difficulty over the years with nursing home regulations, skilled nursing home regulations. I think the Federal and State programs have been legitimately criticized for having a paper-based regulatory system as opposed to a patient or outcome-based kind of system. For example, there is a census of the bedpans in the nursing home. If you have got the adequate number, that is important, but if nobody uses them it does not do anybody much good. You are supposed to have a certain kind of health care professional on the premises every so often, but if that person just walks through very,

very quickly and returns to the sitting room, that does not help very much.

Reimbursement and all the wonderful joys of regulation that it will bring with it, is that really going to be worth it for the hospice? I have tried to paint a terrible picture for you so you do not give me the easy answer. Who wants to tackle that?

Ms. BOHNET. I think it is very important because if we do have standards and criteria and hospices have to adhere to at least a minimum, then we are assuring patients and families that there is a consistency in quality of care that otherwise is not possible if it is hit and miss, like I think I am a hospice but I do not provide 24-hour coverage and I do not do bereavement counseling, but I do everything else. Well, you have got to do everything and you had better do it within the guidelines because if you do not you will not be allowed to be calling yourself a hospice.

Senator HEINZ. To Carol De Moss, our bill, S. 1958, has a requirement that a hospice program offer or make arrangements for inpatient backup care. Would your program do that?

Ms. DE MOSS. Perhaps. I cannot definitely commit myself. I think that part of the problem is that none of the hospitals will cooperate if they know there is a difference in the reimbursement. And there is also the question of whether they would permit us to have control over "their patients." Even more important, if we are going to have a hospice as it should be, we should have control over the staffing and the education of the individuals who provide the care in the hospital; and we do not feel that it would be of any value just for any nurse or other staff to provide the care if they are not aware of and share the hospice philosophy. Whether these points are financially or administratively possible, is of great concern to our agency.

Senator HEINZ. I gather that the problem for them is just like it is for you. Any solutions?

Ms. COHEN. Yes, the thing that might make it a little easier for us is that our skilled nursing component is provided by the South Hills Health System Home Health Agency. That agency provides home care for eight area hospitals as well as our hospice program. As a result staff from the home health agency is based in a number of the hospitals where our patients are hospitalized. We have rapport developed with other hospitals. When you are talking about the physicians, sometimes that becomes a little bit more difficult.

Senator HEINZ. One other question to Carol De Moss. Most hospice programs require the presence of a family or primary caregiver for this program. Your program admits patients without families. How are you able to provide home hospice care to these patients, and are there instances when you are unable to admit patients without families to your program?

Ms. DE MOSS. We do admit patients without families. We did this after a lot of soul searching. We finally came up with the idea that a patient who does not have a family is also entitled to die with all the dignity with which many other people die. What we do is to provide them with care varies. We may increase our own hospice service, but we also try to rally the community and get them more involved. It is amazing what you can find when you go out campaigning the neighborhood and asking, "Will you do this on a cer-

tain day, will you help us out on a certain day? These patients are more likely to die in the hospital than the home, but we have found that most can be at home up until the last few days, and at times, with our increased service and the help of neighbors, they have died at home when that was their wish. So it can be done. It is difficult, but it can be done.

Senator HEINZ. One last question to you all. I understand that your four programs served almost 1,000 people in the Pittsburgh area in the last year. Do you think that the four programs you have meet all the needs, meet all the demands for hospice care in this area? If not, how much more do you think is needed?

Ms. COHEN. We would like to do some statistics on hospice demand. A staff member from the South Hills Health System is helping us assess the demand for home hospice care. I believe with more publicity all our programs will find increased utilization. However, without adequate reimbursement we may not be able to meet the needs.

Senator HEINZ. Do any of you have to turn people away?

Ms. COHEN. We might have to put them on a waiting list or on to a regular generalized home care program until we have hospice staff available.

Ms. DE MOSS. We have the same situation. There is a waiting list in some instances.

Senator HEINZ. How long is the waiting list?

Ms. DE MOSS. That varies tremendously with the help of our staff and any vacancies. In most cases probably a week.

Senator HEINZ. A week?

Ms. DE MOSS. Yes.

Senator HEINZ. And yet I gather—is my impression correct—that people would be better served and perhaps in-hospital stays would be further reduced if people were admitted into your hospice programs a bit earlier than you are able to accommodate them now? So while you said you have a wait of a week, in a sense, that is really not a true measure. It might be better if you were out identifying the people at an earlier point in time, rather than waiting for them to come to you.

Ms. DE MOSS. I agree. As you have heard, our average length of stay is longer than most programs and we do actively seek our patients at an earlier time in their illness. In regards to the 1 week waiting time, in most cases this time is not crucial, especially when they are referred early. If we have a referral for a patient who is very terminal, we do prioritize, and we will admit them immediately.

Senator HEINZ. That's right. Do the rest of you have a waiting period for people to get in?

Ms. COHEN. Sometimes.

Senator HEINZ. Sometimes.

Ms. BOHNET. Sometimes.

Ms. FELLO. Sometimes.

Ms. BOHNET. We deal with approximately 500 physicians and I would say that there are probably 20 who refer to hospice, and I think that would answer your first question about the number of patients who are being referred. There is still a physician reluc-

tance, and there are still patients and families who are reluctant and who are not sure what hospices are all about.

Senator HEINZ. Is there any way to look at the experience of hospices in other parts of the country, those that may have been around longer than any of the four of you, to learn what the number of hospice admissions per 10,000 population might actually be if people were aware of hospices or were that alternative available? You do not have much to go on at the time, do you?

Ms. FELLO. No, but I think in general, you know, when you talk about population affected by a cancer of this kind, as you heard earlier, of that 1 in 4, 70 percent will die from that disease. Now, of that percentage, not all would choose hospice. Some would choose aggressive care and heroics until the end.

Senator HEINZ. Let me ask you this: There are some, just taking senior citizens for the moment, we have some statistics, roughly 300,000 medicare beneficiaries who are expected to die of cancer during 1983, a fraction of that number gets any hospice care now. How many would you guess, from your experience, people 65 and older here, would be good candidates for hospice care, of roughly 300,000 terminally ill cancer patients?

Ms. BOHNET. I would say most of them.

Senator HEINZ. Most of them would, the majority of them, 150,000. Does that seem right to all of you, or would you say it is a smaller proportion?

Ms. DE MOSS. I think probably about half.

Ms. FELLO. I would be a little more conservative. Again, a hospice is an alternative that not all people would choose, even if they are to have that option given.

Ms. COHEN. That is true.

Senator HEINZ. Well, let us try to identify the population that hospice would be a good alternative for, and how many of that group would actually choose it. Of 300,000, you are saying it would be a good alternative for 150,000, or would it be a good alternative for a larger figure than that?

Ms. COHEN. I would tend to agree with Maryanne. I think that 50 percent might be high, although I certainly would like the option to be available.

Senator HEINZ. A second question is, of that 150,000 under your fully informed kind of circumstances, how many might choose it? Half of them? Two-thirds of them? A third?

Ms. COHEN. I would like to——

Senator HEINZ. I mean this is not a statistical question. This is just based on your experience and the things you deal with.

Ms. COHEN. I do not know.

Ms. FELLO. Will you hold me to it?

Senator HEINZ. This is off the record but it is being recorded.

Ms. FELLO. My feeling is that for those 150,000, that it would be appropriate for maybe one-third of the patients.

Senator HEINZ. Maybe one-third. That low? Why? Why, if it would be appropriate for so many, would so few choose it? Why not 150,000? It seems so much more humane, so much more dignified.

Ms. FELLO. I think it has to do with, first of all, a couple of different levels. We are a death-denying society and physicians refuse to

say there is nothing more left to offer, and those patients remain in the acute setting. Many receive chemotherapy until the day of their death. Second, as the situation stands now, even if an alternative seems attractive, if you have to pay for it out of your pocket, you may choose another alternative.

Ms. DE MOSS. I still believe that hospice would be appropriate for half of the patients, perhaps even more.

Ms. COHEN. I think, also, many families will not admit or will not let their dying family member know that they are dying, even though probably the family member who is dying knows that they are playing a game, and as long as that game continues to play, they will be better in a week or a month or a year, hospice will not be appropriate for those people.

Senator HEINZ. Any further comments? Any last words?

Ms. DE MOSS. No, except that hopefully the hospice movement will change some of the thoughts about death. We will be more open about death.

Senator HEINZ. I think it will. I think there are certainly ways to go, but I think that you are changing people's attitudes.

Ms. COHEN. We brought you here today.

Senator HEINZ. You certainly did, and I am grateful. Thank you all very much.

The hearing is adjourned.

[Whereupon, at 11:45 a.m., the committee was adjourned.]

APPENDIX

STATEMENTS SUBMITTED FOR THE RECORD

ITEM 1. STATEMENT OF DENISE KOPPELMAN HARRIS, EXECUTIVE DIRECTOR, HOSPICE OF GREENE COUNTY, INC., WAYNESBURG, PA.

The purpose of the hospice home care program for Greene County is to provide medical, spiritual, psychological, and social support services for persons suffering from an illness diagnosed as terminal, to provide counseling and care for families of such clients during illness and bereavement, to provide a support system to help such persons live effectively in the face of impending death, and to provide quality care while keeping the cost of such care down by supplementing, not duplicating, existing services.

Hospice of Greene County began in December 1977 as a steering committee of concerned persons drawn together from the community in order to assure that terminally ill persons in the county would be able to choose to spend their final days in a familiar environment with compassionate care from families, medical professionals, and other concerned community members. Throughout 1978, members of the steering committee gathered information about the international hospice movement from books, conferences, and a visit to the New Haven, Conn., hospice. Through monthly meetings the steering committee used this information to design a hospice program responsive to the needs of Greene Countians. The steering committee became a legally incorporated nonprofit organization on August 28, 1978, in order to gain further support, both moral and financial, for the effort. The Internal Revenue Service has granted Hospice of Greene County, Inc., a tax-exempt status. A board of directors was established on February 21, 1979, to continue the activities.

Prior to providing hospice care, the steering committee did a community assessment to determine the need for hospice services. It was determined that of the 50,000 people living in Greene County, which covers 577 square miles of rugged hilly country, 85 percent of these individuals were considered rural while the remaining 14.3 percent reside in the county seat of Waynesburg. Greene County has the highest percentage of elderly individuals and has proportionately more families living in poverty than any other county in Pennsylvania. Further study showed that the potential caseload for in-home hospice services for the first full year of care would be approximately 70 terminally ill individuals. Only one home health agency at that time existed in the county, and with their cooperation it was determined that their services would not be duplicated but supplemented through the existence of a separate hospice home care program.

Hospice care was initially provided from January to July 1980, on a pilot project basis for three Greene County individuals and their families. All hospice services for these individuals were provided by a volunteer hospice care team made up of professionals and lay persons. The team members' visits were coordinated by the paid executive director who is directly responsible to the board of directors. The volunteer team members of each of the clients in the pilot project included the attending physician, and clergy members, a registered nurse, a medical social worker, and hospice-trained client aides and family assistants. Whether or not all team members were involved in the individual client's care depended upon the plan of treatment designed for them.

The pilot project was originally designed for the purposes of: (1) Organizing and training volunteers to provide the full scope of needed services in a compassionate and comprehensive manner, and (2) establishing the legitimacy of and the necessity for hospice services to the medical community and to the community at large. Hospice of Greene County, Inc., found the pilot project to be an invaluable (although difficult), method by which the executive director, board of directors, and community at large was enabled to reach the following conclusion: Comprehensive home health services for the terminally ill and their families cannot be provided on an all-volunteer basis overseen by one paid staff person; volunteers do not replace paid po-

sitions, they provide additional services which enhance the care of clients and families and augment the work of the paid hospice staff.

The pilot project led the board of directors to set the priority of securing a sound financial base in order to hire adequate and well-trained staff and thus be able to accept all county residents who are terminally ill, in need of and desiring hospice care. Funding was secured through support from corporations, foundations, and local organizations and citizens allowing for the current staff configuration: an executive director (M.S.W. with health administration background); a client care coordinator (R.N. with home health experience); a coordinator of volunteers social worker (B.S.W.); a part-time hospice R.N., a part-time hospice L.P.N.; a hospice health aide; and a secretary/bookkeeper. Beyond these employees, Hospice of Greene County's medical director volunteers his time, a physical therapist is on contract, and a financial manager has recently been hired to oversee fundraising activities on a commission basis.

After sufficient training, the hospice staff began providing home hospice care on a full-fledged basis on November 1, 1980. After the intital 60 days of care provided to terminally ill Greene Countians, Hospice of Greene County, Inc., became a medicare-certified home health agency on January 7, 1981, allowing for third-party reimbursement (medicare, medicaid, UMWA, Blue Cross, etc.) of skilled services we provide (nursing, social work, aide, and physical therapy).

Third-party reimbursements recover approximately 45 percent of the hospice budget. The remaining 55 percent is recovered through donations (corporate and private), fundraising events and grants. Third-party reimbursement is helpful but does not cover volunteer or bereavement services, along with the specialized types of skilled services Hospice of Greene County provides.

Members of the staff make regular visits and are on call 24 hours a day, 7 days a week, to visit and/or talk to the hospice client and his/her family. Care of the family continues through the period of bereavement. Existing in-home services are not duplicated; rather, hospice coordinates its activities with those of other community social service agencies. No client or family is refused hospice services because of lack of economic resources; every attempt is made to help each family maximize the resources available to them. Criteria for an individual's acceptance into the hospice program of care are: (1) Must be a Greene County resident, (2) have a limited life expectancy documented by a physician, (3) have a primary caretaker, and (4) have a physician willing to assume responsibility for medical direction. Any individual referred to Hospice of Greene County and not eligible for the program is referred to a more appropriate resource.

Hospice of Greene County served 70 clients and their family members during the first full year of care. The client census ranges from 12 to 20 clients at one time with the average length of stay being 3 months. Due to the fact that Greene County has the "oldest" population in the State (15.9 percent of the population, and 32.5 being the median age), 76 percent of Hospice of Greene County clients are medicare eligible, 7 percent are medicaid eligible, and 17 percent are covered through private insurance sources.

Perhaps the most remarkable aspect of the Hospice of Greene County program is its dependence upon a group of specially trained, dedicated volunteers who serve in every aspect of the home care program depending upon their skills and interests. Volunteers are divided into three categories: Client aide (direct personal care to the terminally ill); family assistant (neighborly assistance, errands, transportation, companionship, etc.); and clerical (help in office, answering phone, typing, newsletter, etc.). All volunteers must complete Hospice of Greene County's 20-hour-training program. Topics covered in this training program include: General hospice information, cancer, recordkeeping, equipment used in client care, effective communication, psychological and spiritual aspects of dying, funeral considerations, grief, and bereavement. Hospice of Greene County currently has 150 volunteers who are recruited, trained, and selected under the direction of the coordinator of volunteers. It costs approximately $75 to train each volunteer.

I hope that this information has been helpful to you. A fact sheet is enclosed which we use during our public education programs.[1]

ITEM 2. STATEMENT OF HOSPICE OF YORK, PA.

Hospice of York is a nonprofit, community-based home care program, whose beginnings date back to September 1978. The hospice concept was introduced to the

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[1] Retained in committee files.

York community by the long-range planning committee of the York Visiting Nurse Association.

Several individuals, representing clergy, business, medical and health-related professions formed a hospice committee to study the need and feasibility of a hospice program for York County. The committee surveyed area physicians, health-care organizations, and social service agencies, attended hospice seminars in Philadelphia, and visited Hospice of Northern Virginia. The committee, realizing the great need to better counsel and support terminally ill patients/families, proceeded with the development of a hospice program. A statement of purpose and goals was established as follows:

Hospice of York shall provide for a program of palliative and supportive care for terminally ill patients and their families.

A multidisciplinary team approach shall focus on the special needs of patient and family and help provide a quality of life consistent with those needs during illness, death, and bereavement.

The Hospice of York shall be a community-based, nonprofit organization.

It shall be the initial goal of Hospice of York:

(1) To supplement and coordinate, not duplicate, existing services in the community.

(2) To function with the consent and cooperation of the health care community.

(3) To educate both the lay and professional community about the special needs of the dying.

(4) To offer services and support regardless of an individual's ability to pay.

(5) To provide for spiritual, social, emotional support, and for financial and legal assistance, and other advocacy services.

Permanent officers and board members were elected in April 1979, and an application for incorporation was made. Various committees functioned on an ad hoc basis to study and plan for actual hospice service. Discussions began with a Hanover group interested in hospice, by-laws were adopted, a $10 membership fee was established, a coordinator was hired, the first group of volunteers was trained, and the decision was made to begin accepting patient/families in January 1980.

The goals established by the hospice committee remains the same today. Hospice of York is staffed by a full-time coordinator, an administrative assistant, a part-time counselor and secretary, and 67 trained home-care volunteers; and our Hanover satellite hospice program, staffed by a part-time coordinator, assistant coordinator, and 12 home care volunteers have provided special supportive services to approximately 235 (this number includes the period from January 1, 1980 to December 31, 1981) patient/families in York County since January 1980, at no charge to these families.

Patients are eligible for hospice care when active, aggressive treatment for a cure of their disease has stopped, and their life expectancy is measured in weeks or months—usually 6 months or less.

The patient and family must be aware of the diagnosis and life expenctancy. It is not required that they have accepted this fact. Hospice staff and volunteers will not initiate or force inappropriate discussion. Hospice is there to listen when the patient and family want to share and discuss. A primary caretaker must be in the home or immediately available. Hospice supports the family but does not replace it.

Referrals come from a number of sources: Families, patients themselves, physicians, social service workers, clergy, visiting nurses, and other health-care agencies. Once hospice receives a referral, a phone call is made to the family to gain additional information and an appointment is scheduled for the coordinator to visit and make an assessment of the needs of the family. During the first and subsequent visits, the coordinator provides support, counseling, and acts as patient/family advocate. Volunteers are placed to offer support and respite to the family.

Volunteers are a special component of the care-giving plan. They are members of the community who want to give their time and friendship and are required to complete an intensive 33-hour training course before becoming involved with a hospice family. Once involved, their duties may vary and depend on the needs of the family. They visit the home and may do cooking, housekeeping, taking care of children, or sitting with the patient so that family members may shop and run errands. Above all, hospice volunteers offer love, friendship, and caring. After the patient's death, the volunteer remains involved to help the family cope with emotions and adjustments during the bereavement period.

Beginning November 1, 1981, York Hospital developed a backup system for hospitalized hospice patients in order to provide a more homelike setting. When a patient must be admitted, he/she will go directly to these designated beds, omitting usual admitting and lab procedures. The rooms may be decorated with afghans, plants, etc. Family members have special visiting privileges, and, with special permission,

pets may also visit. Special efforts are made to prepare whatever food the patient wishes to eat, whenever she/he wishes to eat it. Hospice staff and board members are meeting with representatives from Memorial Osteopathic Hospital to begin such a program at Memorial. These beds are available to our patients for short-term, critical care situations.

The staff of Hospice of York is available to patient/families 24 hours a day, 7 days a week, through the courtesy of the York Hospital paging system.

Family members are an important part of the hospice team. This team includes the physician, visiting nurse, home health aide, clergy, and trained hospice volunteers, together with the patient and family, all sharing in the care-giving process.

Every family structure is unique with its own needs. The flexibility of Hospice of York helps our families to overcome problems and meet these needs.

Hospice is helping a 9-year-old boy understand where his father went when he died last night—answering questions, "What is going to happen at that thing I have to go to tonight?"

Helping Bill and his children think through scheduling family and hospice home care volunteers to give Mary the privilege of remaining at home and Bill the peace of mind to hold onto his job.

Helping rearrange the Smith's living room to give grandma her very own corner of the world still in the center of family affairs, yet affording her the colors and comfort of home in a hospital bed.

HOSPICE OF YORK

Volunteer Training Program III

1981

March 2 & 5

Introduction to Hospice Care
I. Introduction and Course Review
Hospice - Past, Present, & Future
film, "Hospice"
Living with Illness
The Role of the Volunteer
Hospice Coordinator and Volunteer
Questions and Answers

March 9 & 12

II. Introspection & Self Development
Exploring your personal feelings
Concrete Skills
Coping

March 16 & 19

III. The Culture and Tradition of Death and Dying
American Tradition of Death
Personal Reflections on Death
Legalities of Death

March 23 & 26

IV. Communication
How do we?
Verbal, nonverbal, & listening
film, "Peege"

March 30 & April 2

V. Communication Skills & Sensitivities
Active Listening, body language
Problem Solving
film, "Shopping Bag Lady"

April 6 & 9

VI. Cancer & Other Life Threatening Illnesses
Cancer the Disease
Cancer therapies and appearances
Pain Control
film, "Dying"

April 13 & 16

VII. Community Resources
Visiting Nurse Association
Hospital Oncology Nurse
Area Agency on Aging
Family Services
American Cancer Society
Clergy
Social Services

April 20 & 23

VIII. Care for the Caregiver
Coping, Relaxation
Stress
Physical, emotional & spiritual outlets

April 27 & 30

IX. Grief & Bereavement
Psychology of Grieving
Death, Funerals, and After
Physiology of Death

May 4 & 7

X. Basic Physical Care
Beds, bedpans, & wheels
Psychology of touch

May 11 & 14

XI. Hospice of York
Getting Ready
Family Assignments
Confidentiality & ethical considerations
Paperwork and teamwork

HOSPICE OF YORK
Budget Preparation Form
1982

Line Item	81 Budget	81 Year End Projected	82 Func-Admin. York-Hvr.	82 Func. Fund Rsg.	82 Func. PF/PR	TOTAL
alaries	27,000	32,888	51,558			51,558
enefits	705	745	515			515
axes	1,800	1,746	2,250			2,250
ent	1,200	1,200	1,200			1,200
ffice Admin. Supplies Printing Copying	1,200	569	775		488	1,263
quipment	1,500	5,845	403		350	753
elephone	1,300	1,411	1,400			1,400
ostage	1,000	1,126	450	420	308	1,178
ravel Pt.Prog. Staff/Vol.	1,000	2,295	2,904			2,904
ducation Community rofessional Volunteer Staff	1,600 (500) (350) (750)	771 (372) (212) (187)	1,650		940	2,590
cct.& Legal Fees	300	1,090	780			780
nsurance	645	698	550			550
ospice Organization a) Dues b) Conf. & Conven	525	525 791	525 850			1,375
iscellaneous	500	796	250		90	340
iscretionary			550			550
nnual Meeting					260	260
OTALS	40,275	52,496	66,610		2436	69,460

1982 Func. Adm. York includes salaries for:
part-time caseworker. - - - (15 hrs/wk X $6/hr = $4,680)
part-time Medical Director (3 hrs/wk X 30/hr = $4,680) TOTAL $9,360

leted items from 1982 proposed budget:
- $270 accounting fee
- 1000 projector and film
- 250 slide projector
- 30 decorations, annual mtg.
- 170 Insurances (all combined under St.Paul Ins. for lower rate)
$1720 TOTAL

HOSPICE OF YORK

BUDGET PREPARATION FORM

1982 INCOME

LINE ITEM	81 BUDGET	81 YR. END PROJECTED	YORK 82 York-Hanover
Memberships & Pers. Contributions	$6,000	$10,500	$15,000
Memorials	2,000	6,110	8,000
Foundations	2,000	6,500	7,500
Business & Industry	2,000	2,000	5,000
Honoraria	250	600	600
Churches	NA	9,000	10,000
Clubs & Organizations	2,000	5,000	7,000
Special Projects: a) LKO/Avon	5,000	10,000	11,000
b) Other	10,000 (Young Women's Club)	10,000 (Young Women's Club)	1,866
Education Projects	NA	NA	1,500
Designated Gifts		0	
Interest	NA	1,849	2,000
Total	$35,250 6,000 Hanover	$61,559 Including Hanover	
GRAND TOTAL	$41,250		$69,466

ITEM 3. STATEMENT OF MADALON O'RAWE AMENTA, R.N., PH. D., PRESIDENT, PENNSYLVANIA HOSPICE NETWORK, PITTSBURGH, PA.

The Pennsylvania Hospice Network is an officially incorporated association dedicated to the furtherance of quality hospice care and the promotion of the hospice concept in the Commonwealth of Pennsylvania. It began with a convening meeting called at the National Hospice Organization annual meeting in November 1979. Since that time it has maintained a membership level of between 50 and 60 operating hospice programs comprising every major model to have emerged in the United States, and 70 to 100 interested individuals. It conducts an annual meeting at which figures of national prominence in the hospice movement give keynote addresses, and clinical as well as administrative, reimbursement, and legislative issues are treated in workshop format. Elected and appointed officials of State government, as well as others with influence at the State level, e.g., the Governor's wife, attend the luncheon and contribute supportive statements.

Network News, the newsletter, is distributed quarterly to a mailing list of over 350. It contains information about various member hospice organizational models, news of members, updates on legislation and reimbursement actions, notices of workshops and printed educational materials, and a listing of cassettes in the ever-expanding tape library that rotates on loan, at cost of postage. The newsletter is reproduced and mailed by the American Cancer Society, Pennsylvania division, as part of its contribution to fostering hospice care in the Commonwealth. The Cancer Society also underwrites part of the cost of the annual meeting.

The network participates in the deliberations of the Interdepartmental Task Force for Hospice, a group representing all relevant government departments, which is developing recommendations about the most appropriate and effective State role in hospice support to submit to the secretary of health and through him, the Governor.

The network is the State structural unit of the National Hospice Organization, carrying a vote at annual meetings and in the regional body, to which it sends three official delegates. It also votes for the regional delegate to the National Hospice Organization board of directors.

The Pennsylvania Hospice Network has officially, from its inception, endorsed the principle of legislation in support of reimbursement for hospice care. Some of its board members are active in the national hospice education project. All work diligently through their own individual hospice organizations to engage a broad base of knowledgeable and concerned people—advisory board members, volunteers, patients' families—in the grassroots legislative process of contacting elected officials by mail, telephone, and in person to advocate a hospice benefit in the current official reimbursement structures. It is stressed that the advantages to be derived will not only be humane, but cost-effective, as well. The Pennsylvania Hospice Network will continue to work through the channels open to all citizens and those additional ones provided by the local, regional, and national structures of the National Hospice Organization, and its endorsed affiliates, for the best possible legislation to provide a realistic and sound choice for those families wishing to make the death of a loved one a primal family event.

ITEM 4. STATEMENT OF BARRIE R. CASSILETH, PH. D., DIRECTOR, PALLIATIVE CARE PROGRAM, UNIVERSITY OF PENNSYLVANIA CANCER CENTER, PHILADELPHIA, PA.

The University of Pennsylvania palliative care program represents a particular expression of hospice care: A scattered-bed model situated in an acute-care, academic medical center. We are pleased to comply with Senator Heinz' request for a description of our program as an example of such a model.

As requested, this report outlines the program's initiation and functioning, and provides data on patients served in the 21 months of the program's existence. It is hoped that this testimony will both elucidate the architecture of this type of program, and support the need for hospice activity whatever its structure or setting.

BACKGROUND

Hospice is palliative care; care rendered when disease no longer is amenable to active treatment, and when comfort, rather than cure, becomes the realistic goal. Our need for a hospice program surfaced as it became increasingly apparent that existing services could not meet the unique and substantial requirements of our terminally ill patients and their families.

Therefore, the possibility of establishing a separate service for this patient population was considered. A needs assessment survey was conducted, consisting of interviews with University Hospital administrators, patients, physicians, nurses, and other health professionals. The survey confirmed the need for a hospice service and provided guidance for the development of its goals, structure, and content.

Goals adopted for our program, similar to those of hospice activities generally, focused on maximizing the quality of life for terminally ill patients and their families. Particular emphasis was and remains placed on the management of pain and other symptoms; on the provision of counseling and other support; and on enabling home care where desired and feasible.

Administratively, the program was developed under the aegis of the University Cancer Center. The vast majority of hospice patients throughout the country are cancer patients. Governance is provided jointly by the administrator of the Hospital of the University of Pennsylvania, and the director of the University of Pennsylvania Cancer Center.

It was determined that a scattered-bed model, rather than a geographically isolated unit, would function most effectively and would permit the most efficient use of beds in our particular setting. There were philosophical as well as practical reasons for this decision. A scattered-bed arrangement means that patients are cared for wherever they are located throughout the hospital. This arrangement avoids the negative feeling tones sometimes associated with a "death and dying ward" or with an isolated unit for terminal patients. It also provides the benefit of continuity of care. The patient is not removed or readmitted, at what may be an arbitrary point in time, away from the hospital section to which he is accustomed and taken to a separate place for dying.

The scattered-bed model also allows for maximum flexibility with regard to inpatient bed utilization. The number of hospice inpatients at any one time is variable. Beds in an inpatient hospice unit might go empty, an important consideration when hospital beds are at a premium. Conversely, the hospice bed allotment in a segregated unit occasionally may be inadequate to house the number of hospice patients in need of inpatient care at that time.

Burnout can be a serious problem among nurses and other health professionals who work in stressful inpatient environments, such as intensive care and hospice units. The scattered-bed hospice model obviates this problem, both because responsibility for terminal inpatients is shared by hospital staff, and because hospice personnel are not restricted to a small unit exclusive to dying patients.

A final consideration concerns the issue of whether isolating terminally ill patients serves their best interests and whether that approach is ideologically preferable. Our bias favors integrating these patients with others, an arrangement that reflects the continuum of life and death.

We recognize the need for some long-term inpatient hospice facilities, particularly for those patients who require continuing attention and who cannot be maintained in their homes. However, the vast majority of patients served in our program do not require long-term, continuing inpatient care. The combination of home care plus scattered-bed inpatient service has proved effective for our population.

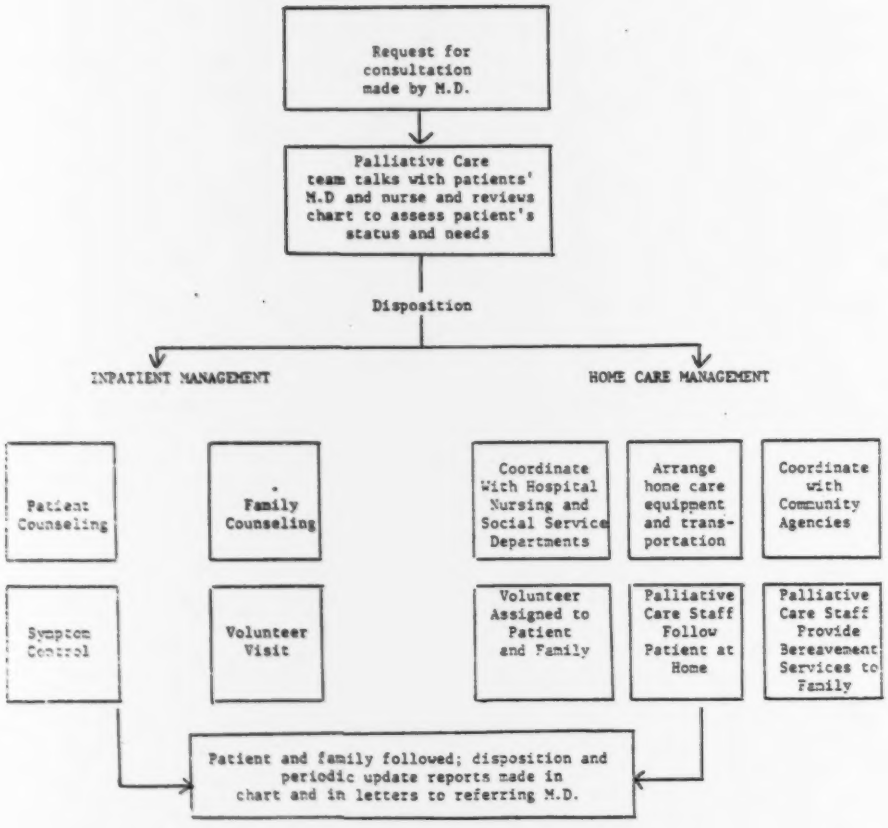
An important service that cannot be provided without an inpatient hospice unit is respite care; admitting the patient so that the family can be relieved temporarily of its caregiving responsibilities. We attempt to compensate for our lack of a respite capacity through the use of volunteers who provide similar caregiver-relief functions.

Description of Program

In September 1980, our palliative care program began. The original structure and functioning of the program have worked well and have not been fundamentally altered.

Terminally ill patients, regardless of diagnosis and whether they are hospitalized at the time, are referred to the program by University Hospital physicians. A nurse and a counselor from the palliative care team then visit the patient and family, review the patient's hospital record, and talk with the physician and with others who have been involved with the patient's care. The patient accession procedure is summarized in the following chart.

PATIENT ACCESSION AND DISPOSITION


Request for consultation made by M.D.
Palliative Care team talks with patients' M.D and nurse and reviews chart to assess patient's status and needs
Disposition
INPATIENT MANAGEMENT
HOME CARE MANAGEMENT
Patient Counseling
Family Counseling
Coordinate With Hospital Nursing and Social Service Departments
Arrange home care equipment and transportation
Coordinate with Community Agencies
Symptom Control
Volunteer Visit
Volunteer Assigned to Patient and Family
Palliative Care Staff Follow Patient at Home
Palliative Care Staff Provide Bereavement Services to Family
Patient and family followed; disposition and periodic update reports made in chart and in letters to referring M.D.

Palliative care staff continue to work with the patient and family throughout the course of illness. Close collaboration with the patient's physician is maintained. Bereavement counseling is provided to family members, as needed, for 6 months or more after the patient's death.

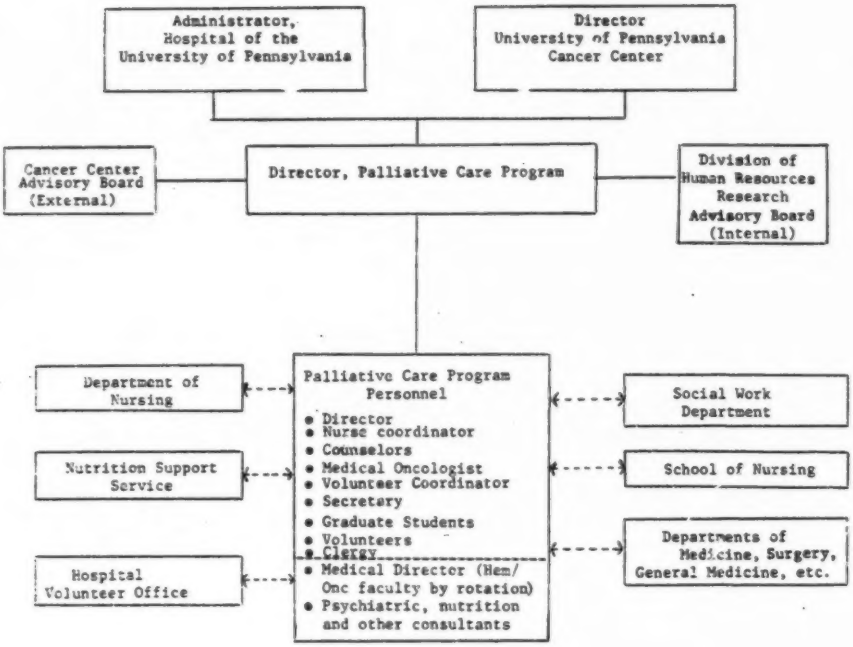
Program personnel consist of a program director, a nurse-coordinator, two part-time counselors, and two graduate students each in nursing and in social work or psychology. (The graduate students' part-time, minimum 1-year involvement in the program also constitutes fulfillment of the internship requirements of their academic programs.)

A rotating medical directorship involving seven senior hematology/oncology faculty members enables assistance as needed from physicians in addition to those already involved with the patient's care.

Volunteers constitute a vital component of the palliative care team. Volunteers are carefully screened and selected, and complete an 18-hour training program. They work in patients' homes, assisting in ways that are needed by the particular patient and family, and attend to patients when they are hospitalized. Monthly meetings with the volunteers are held at the hospital.

Our University Hospital location offers many advantages, including the proximity of psychiatrists, clergy, nutritionist, physical and occupational therapists, and other professionals who are available to assist as needed. The following chart indicates program personnel and organization.

PERSONNEL, ORGANIZATION, AND LIAISONS


Administrator, Hospital of the University of Pennsylvania
Director University of Pennsylvania Cancer Center
Cancer Center Advisory Board (External)
Director, Palliative Care Program
Division of Human Resources Research Advisory Board (Internal)
Department of Nursing
Nutrition Support Service
Hospital Volunteer Office
Palliative Care Program Personnel
• Director
• Nurse coordinator
• Counselors
• Medical Oncologist
• Volunteer Coordinator
• Secretary
• Graduate Students
• Volunteers
• Clergy
• Medical Director (Hem/Onc faculty by rotation)
• Psychiatric, nutrition and other consultants
Social Work Department
School of Nursing
Departments of Medicine, Surgery, General Medicine, etc.

Palliative care staff arrange for any community services that may be needed to assist the patient at home, and work closely with visiting nurses, homemakers or other local agency personnel involved with the patient, insuring optimal coordination of care. Program staff also make home visits when appropriate. The palliative care team meets weekly to review the status of each patient and to reconsider goals and plans. Service is provided at no charge to patients. Twenty-four hour coverage is maintained via long-range beeper. Staff support group sessions, held on alternate months, consist of hospice team members from nine area hospice programs in addition to our own. Meetings are held on a rotating basis at each institution.

Education and Research

Educating other health professionals to the needs and management of terminally ill patients is an intregral programmatic feature. Informal training occurs daily as palliative care staff work with hospital physicians, nurses, and other personnel. Structured presentations are given several times a year to various departments and sections of the hospital.

Palliative care program staff, augmented by other university faculty, mounted a 4-week, full-time course on hospice care last year. The course was sponsored jointly by the university medical school and the university's interdisciplinary health care program, and included students from the schools of medicine, nursing, health care administration, social work, and the Philadelphia College of Pharmacy. It is anticipated that this course will be held every other year.

Evaluation of the program is a component of a broader research project supported by the National Cancer Institute. The relevant portion of the research activity will permit comparisons of psychosocial status between palliative care patients and terminally ill patients at the University Hospital who are not referred to the program.

Patient Data

To date, a total of 253 patients and their family members have been cared for by the palliative care program. Demographic data are available and reported on a total of 227 patients.

Data that summarize the complete course of program services are available by definition only following the patient's death. Therefore, data on average length of care, place of death, etc., are based on 161 patients who have died. Complete information on each patient is computerized following the patient's death. Data on patients and on services provided follow.

PATIENT DATA*

1. Total number of patients seen in Program to date: 253 (49.8% men; 50.2% women)

2. Average number of family members per patient seen in Program to date: 3

3. Current case load: 30 patients

4. Number of families followed for frequent bereavement care: 112

5. Patients Age: Range: 1-93 years; mean age: 57 years

6. Patients' Race: 67% white; 32% black; 1% other

7. Patients by Diagnosis

	Malignant Diseases	% of Patients
1.	Lung	14.1
2.	Breast	15.4
3.	Hematologic	5.7
4.	Pancreas	7.0
5.	Other Gastrointestinal	7.9
6.	Colorectal	8.8
7.	Melanoma	5.7
8.	Genitourinary	7.9
9.	Gynecologic	4.0
10.	Brain and other CNS	5.7
11.	Head and Neck	3.5
12.	Soft tissue	4.0
13.	Other malignant diseases	8.5
14.	Non-cancer diagnoses	1.7
	TOTAL	100

8. Occupation:

Blue Collar	11%
White Collar	14%
Professional	5%
Student	1%
Homemaker	14%
Retired	49%
No Information	6%

9. Insurance Coverage:

Type	% covered by	% not covered by
a) Medicare	33%	49%
b) Medicaid	11%	71%
c) Blue Cross/ Blue Shield	43%	40%
d) Other	17%	66%
e) Disability	2%	81%

(No information on 17 - 18% of patients)

10. Average length of care for 161 deceased patients: 76 days

11. % time at home vs. hospital while in Program (deceased patients): 75% home; 25% hospital

12. % time in hospital for all patients in one calendar year: 20%

13. Place of death: 28% at home; 68% in hospital; 4% other

*Data are calculated for the entire 21 months of the Program's existence (September, 1980 through June 9, 1982).

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